Episode 124 - Amanda Hunsaker: Advances in Dementia Diagnostic Technology: Preparing Social Work for a Changing Practice

[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 in social work. I've spent a couple of years now telling you about all the delightful things that are related to living in the Buffalo area. Weather wise August and Buffalo is perfect and if you want to branch out a bit how about a 25 minute car ride to Niagara Falls. 90 minutes to Toronto. Thirty five minutes to the Shaw Festival in Niagara on the lake Ontario or a little more than an hour to the Chicago institution. An adult education center and summer resort were big thinkers gathered to partake in offerings organized around the arts religious ideas and recreation. I'm Peter Sobota in this episode our guest Amanda Hunsaker draws on her background in public health and her current doctoral studies to discuss the current landscape related to the diagnosis and treatment of Alzheimer's disease and how advances in diagnostic technology associated with dementia will provide the potential for new insights in the care of these patients. She begins by providing some sobering statistics related to the prevalence trends and the impact on health care costs related to Alzheimer's disease. She goes on to examine the lack of diagnostic and treatment processes that characterize the current state of this field. Ms.

[00:01:56] Hunsaker comments on the role social workers who work with patients can play in diagnostic and care planning and how their skill set is particularly well suited to the needs of these patients and their caregivers a doctoral student at the University of Pittsburgh School of Social Work. Ms Hunsaker provides extensive commentary and recommendations about the future of diagnostics and treatment in this field including the role that biomarkers will play in diagnostic efforts related to Alzheimer's disease. She concludes by discussing the impact of the developing technological advances in this field of social work practice especially as testing options become more available Amanda Hunsaker LSW ph is a doctoral candidate at the University of Pittsburgh School of Social Work. Her research interests include care decision making issues for individuals with Alzheimer's disease and their caregivers and the process of communication among people with cognitive impairment and the process of communication among people with cognitive impairment and their health care providers. Rachel Rotach LSW is director of advocacy and early stage programming at the Alzheimer's Association of Western New York. Here in the Buffalo area and an alum of the UB School of Social Work the statistics Miss Hunsaker referenced in today's interview were taken from the Alzheimer's Association Hi my name is Rachel Rotach. I am a social worker at the Alzheimer's Association. My role as director of advocacy and early stage programming here and today was Amanda Hunsaker. She is from the University of Pittsburgh and is here to talk a little bit about advances in diagnostic technology for dementia and how it will impact social work. Hi Amanda. Hi Rachel thanks so much for doing this interview. For those of us not familiar with Alzheimer's disease could you give us a description of that. Sure.

[00:04:03] So Alzheimer's disease for 80 years a lot of people call it progressive and terminal brain disease and it impacts cognitive abilities that interfere with daily life activities. So things like remembering new information and remembering names for appointments problem solving thinking abstractly and making sound judgments all become more difficult. It's just a really substantial unfortunately about five point four million individuals in the U.S. alone have Alzheimer's and it's the sixth leading cause of death in our country. And we know that age is a huge risk factor for Alzheimer's disease. So about 13 percent of individuals over the age of 65 have these. And this prevalence dramatically increases to almost one in two or 45 percent for people who are 85 years or older. So as life expectancies are increasing and the baby boom generation is aging the number of individuals with AIDS is really expected to surge. There are estimates that by 2025 about six point seven million older adults will be affected by AIDS which is a growth of some 30 percent from current estimates today. So the cost to our expenses cost to the health care system and to caregivers and also to patients payments for a long term care health care and hospice for people with dementia are expected to grow from the current members in 2012 of 200 billion to one trillion in 2050. Medicare and Medicaid really shoulder a lot of these costs. They cover about 70 percent of these health care costs. So also when we look at mortality data and look at death rates for many major diseases such as stroke and prostate cancer breast cancer HIV AIDS and heart disease. We've really been seeing a decline in the death rates from these illnesses.

[00:06:10] And unfortunately we're not seeing the same thing for Alzheimer's disease. Death rates has increased to 66 percent from 2000 to 2003 and it seems that the real reason for this is that there is no medication currently that can slow or prevent as good medications that can slow the progression of memory symptoms and that can treat behaviors related to Alzheimer's disease but really no medication to cure it. So that really seems to point to care planning and care coordination and supportive services are provided through social work is how individuals really can be helped supporting the caregiver has really been a focus of social service systems and of care coordination and that's really because family members experienced significant and they clock in an estimated 17 billion hours of unpaid care that was in 2012 and that was valued at more than two hundred and ten billion dollars in unpaid care that was given in family caregivers report very high levels of stress and depression there Carol can adversely affect their health their employment situation and their financial situation. And of course it's been studied this disease of course very much affects the person who's experiencing this illness. There's this progressive loss of cognition that individuals are experiencing in a progressive loss of functional abilities. And there are also negative outcomes such as anxiety and depression and psychosis that can develop Alzheimer's disease. So given the stark experience of dementia that the burden that it places on families and care systems there's really been a move to improve diagnostic and treatment processes. And this has really been a key focus of Alzheimer's disease research. And what are the current diagnostic processes for Alzheimer's disease right now.

[00:08:19] So currently there isn't any one test for Alzheimer's disease. Unlike other illnesses there's no definitive blood test that tells whether an individual has Alzheimer's disease. So the assessments that are used are multi components and include interactions with a range of healthcare providers. So they include medical or neurological evaluation taking a medical history to understand previous disease history and family history completing neuro psychological testing or mental status testing to look test orientation the time and place testing learning of recall of information and problem solving and attention processing speed. And in addition there also can be brain imaging or blood work done which is very much more to rule out other conditions that cause memory problems. And so it's very much a diagnosis of ruling out other conditions that can cause a similar symptom pattern such as an adverse effect from a medication or a depression thyroid problems or something like a brain tumor. All these things could give a similar symptom pattern and can be ruled out a lot of the assessment also depends on a report of symptoms from the patient and their families as to whether there has been a noticeable change that the patient and family can provide insight into. So with this assessment process we're 90 percent or more accurate in diagnosis. We're not perfect but getting there. And another part a growing part of assessment is using new diagnostic recommendations that include the diagnosis of mild cognitive impairment or MCI. And this captures individuals who are experiencing declines in memory that are noticeable but their ability to carry out daily activities is still intact.

[00:10:19] So these folks might have difficulty with remembering important information that they would have previously remembered or remembering and carrying out steps to complete certain more complicated task. So diagnosis for MCI is very much based on clinical sent symptom of war than and also doing this neurocognitive testing and less on a process of learning how the other conditions. But overall with that diagnosis as NCI and also with earlier diagnosis of dementia it all points to individuals who are diagnosed to have more time and ability to participate in counseling airplane and that also allows clinicians to be able to better identify people who are most at risk and to target treatment to those individuals. For those of us who are social workers or for the people who want to be social workers what would you say their role is in the dementia diagnosis and care plan. Social work really seems to have a wide range of rules currently very much in healthcare and in different kinds of social service organizations. So there are social workers who are providing support and education to caregivers through support groups. So social workers may be facilitating support groups to help caregivers talk with other caregivers about how to cope with different aspects of this illness. Social workers also are part of assessment and implementation of care plans for current and future support. So these assessments might be looking at a need for support with daily activities or support with medication management or with homemaking. Social workers also do a lot of referral and hopefully the Alzheimer's Association does a lot of referral and other resources that might be useful for families in that.

[00:12:19] And they also provide assessment of the environment of the patient and what needs there may be for adapting or changing the environment for that patient to make it safer. So it could be addressing safety issues like wandering or maybe looking at social engagement and improving the social engagement of the person with dementia. So maybe there would be involvement in adult day care to help stimulate the patient socially but also provide respite for the family member. And then of course advocacy and of course the Alzheimer's Association has great critical involvement and advocacy for patients and families to improve how care is delivered for these families. And also just to improve the state of research for diagnosis and treatment. So much of support that social workers provide seems to go to family caregivers and those isn't really changing though that there's been more of a focus on the patient and to the patient and family as a care dyad. So there's been more focus on understanding the experience of the person with dementia. Thereby understanding the behaviors and emotions of the patient in relation to what their experience with this whole mess. So along with this there's been sort of a merging within social work a medical model of care and more of a social model of care for people with dementia under the medical model. There is very much symptoms are diagnosed and treated. There's a biological cost that underlies those symptoms and the diagnosis and evidence based practice is put into place to treat the symptoms. I found this and that more of a social model of care impairment really is considered to be is more within the environment or interacting with the environment. So there's more of an interest in supporting that the unique experience as an individual and what role they may play themselves and training their role.

[00:14:23] So social work has been key in really merging these models of care where symptom treatment can very much help alleviate this memory changes and reduce behaviors related to the venture. But where the person with D also has their own individual experience that matters and that they can be supported and they're meaningful participation care decisions. So this seems to be how social work has really been at the forefront of dementia care. You're clearly an expert in this field right now but I'm curious what sparked your interest initially and dementia detection technology before moving to Pittsburgh. I was living in Atlanta and work that Emory University was Victoria Phillips in this school of public health and I got to work with her on several studies that were developing a new assessment tool for Alzheimer's disease related behaviors and I'm using this tool with clients and family caregivers in a home and community based Medicaid waiver program. We are finding first that a large number of the clients in the program had cognitive impairment and further a large number also had dementia and behaviors that families were having difficulty with managing and really needed support in how to manage those behaviors. So I worked on another study with Dr. Philips looking at the effectiveness of a team based approach to ways to help families and paid caregivers manage these days here. And this approach partnered care coordinators are social workers and nursing supervisors and home care aides and families and the assessment and care planning and monitoring of them and surely did behaviors and monitoring care burdens.

[00:16:14] And what I really took was that there is an important emphasis on this multidisciplinary approach to them and should care and to focus on improving the quality of life of the person with dementia and their caregivers. And I was also really struck by working with social workers and their approach to quite a bit of work. It's really incredible to me. After moving to Pittsburgh I began working in dementia research the Alzheimer's Disease Research Center at the University of Pittsburgh and also with Jennifer on physician patient caregiver Communication Studies and through this work I became more interested in shared decision making and the role of the patient in care decision making especially with dementia. So I started a joint MSW Ph.D. program at University of Pittsburgh and really was supported by an interest in the rooms and race angle and further investigating shared decision making dementia care and long been in school. A lot of significant developments around diagnostic tools for aid were going on at Pitt led by both clonk and Chad Mathus and their work in early detection for Alzheimer's pathology. Really I'd need to think about how these technologies would change the role of social and practice in dementia care and also the need for a shared decision making approach with these of these technologies. And I know you've mentioned earlier some changes in the diagnostic process and I'm wondering how will this continue to change in the future. Do you think. Yeah so you're right Rachel the change was having MCI as part of the diagnostic process has really made a huge difference. And in addition to these clinical indicators research on biomarkers for dementia is really underway. So biomarkers are tools that can predict or indicate a disease process.

[00:18:14] The word could be considered a proxy for their disease processes present or is likely to dissolve. For example was cholesterol cholesterol effective a biomarker for heart disease and those with high cholesterol are treated with an anti cholesterol occasion to reduce that risk of heart disease. So the same could be said of proteins in the body that increase the risk of Alzheimer's disease. And that includes measures of beta amyloid or how proteins in the body that are both considered turns out in these hallmark abnormalities in the brain amyloid plaques are nerve February tangles that are both considered signs that aiding pet allergies. So there are four main types of biomarker tests cerebro spinal fluid testing and blood testing and genetic profiling and brain imaging. And with cerebrospinal fluid or CSF testing there are proteins and CSF that are measured and samples taken to a lumbar puncture and these tests very much focus on measuring levels of beta cannelloni or how proteins in the CSF that current work is really trying to better standardize procedures for measuring these proteins can do meaning to enhance the proteins and the cerebral spinal fluid. There are also blood tests that are doing similar things and measuring levels of beta amyloid or Tau and Blyde. And again the work is really around trying to better standardize how these procedures are done. Another big area is around genetic profiling. So we know that there are genes that are deterministic porn that cause Alzheimer's disease and that's true for a very small percentage of individuals who have HIV. And then there are also genes that we know identify a risk for Alzheimer's disease.

[00:20:09] And there is a lot of work underway to better understand the meaning of that risk and how that information can be made useful to patients that are interested in undergoing genetic profiling. Brain imaging is another area of development. So there are different methods to look at brain volume or shrinkage to look at the uptake of glucose or shiver in the brain that's needed for memory and problem solving. But again there isn't yet a set criteria for determining a diagnosis from these tools. The one killer imaging is an area that's really been growing with brain imaging and Molecular Imaging uses pet imaging and radio tracers that are inserted in the bloodstream to detect a chemical sounds really a level change that's related to disease process. And these technologies can detect amyloid beta in the brain. Pittsburgh compound B rapid warns the first radioactive tracer to be used with patte for Alzheimer's disease and to be used on living humans and it combined to amyloid beta in the brain and make that amyloid visible in pet scanning. And so Pipp has been widely used in research and it's making its way also into the clinical setting. There are other compounds that also exist and they've been developed that enzyme to amyloid a sister compound to parrot is an acid and it's recently been approved by the Food and Drug Administration in April 2012 and it's indicated for use with individuals with cognitive impairment who are undergoing an evaluation for AB or another type of cognitive decline. So unfortunately the Centers for Medicare and Medicaid services aren't yet covering the pharmacy and the cost around about 3000 dollars since the cost is substantial to folks but really the reason seems to be that cims isn't covering it is related to the state of treatment that there isn't.

[00:22:15] What could be considered a treatment that slows the progression of the disease currently and the testing right now isn't really viewed as a way to improve outcomes for individuals with cognitive impairment or improve the management of cognitive impairment. So there's work underway to really address the issue and to build evidence that using amyloid imaging can really change how clinicians manage on this. Oh this research seems to show that we're moving towards the direction of having using animal testing in the present Madec stages or when an individual is diagnosed with MCI. So as far as how amyloid that position builds in the brain it seems to be a very slow process and it occurs over a long period of time and studies are showing that an individual with no symptoms of Alzheimer's disease can have amyloid in the brain so that may mean that individuals will be using these biomarkers that indicate the presence of a hallmark allergy when they're a symptomatic. So this really has significant implications for dementia care practice and for how diagnosis is perceived and how the illness is as far as these technologies continue to develop and likely improve what kind of impact will that have on social work practice. It seems to be there are just three key areas of development dementia diagnosis. Individuals may be better able to differentiate the underlying causes of dementia process. So where there is uncertainty about the kind of dimension individual has this could help to differentiate for example between Alzheimer's disease and other kind of dementia such as frontal deployment dementia. It also may help us to better their earlier diagnosed cognitive impairment.

[00:24:13] So for an individual that knows with mild cognitive impairment we might be more definitively able to determine whether MCI is in the eating process and help to distinguish it from other conditions that could be causing the symptoms. So we may also be able to diagnose people and increase symptomatic stages. So although it's currently recommended against using these tools that may be changing and it seems to be the reasons that are not currently recommended because among cognitively normal people we're seeing that there is an increased incidence of positive amyloid findings among these individuals. So we don't know whether these folks are going to progress to dementia. And there are also older adults so there may be you misunderstanding at play for these individuals but it does point to the usefulness in determining who does and does not have them in their brain. And also how to help people understand results from completing this kind of imaging. And it also opens up a lot of questions for sorting out who should complete such biomarker testing and figuring out who that would be. So would it be individuals with a family history or someone with memory complaints but no diagnosis of impairment. And also will be of great help in determining who would be treating candidates and better treatment for the heart. And another big area that seems especially important for social work is that it opens up questions about how individuals might be counseled and the importance of providing clear information and pre counseling before undergoing amyloid imaging and post-test counselling. It seems to me that social work needs to be a part of providing counseling given that they already have this very prominent role in dementia care.

[00:26:13] So in conducting diagnostic counseling communication can be adapted then it's a very useful framework for discussing the use of biomarker testing and the ramifications of the diagnosis. And this protocol uses a shared decision making approach that walks the patient and their families through developing an understanding of the risk and the seriousness of the possible outcome and developing an understanding that the testing process and what the risks and benefits are of actually doing the testing. What alternatives there might be the testing and the certainty is that the findings are related to the testing and also help people think about weighing their own values that they place on the benefits and risks that could be associated with testings for example would there be an impact on the family stringing her around decisions about long term care and then really in the end to engage the family in the patient's decision making process and to help them come to a decision that they had come for. So when applying pretest counseling specifically more to him than anything this would really helps people make informed decisions about whether to participate in testing and what different outcomes from testing could mean. So this process might start with assessing the patient and family schools and their current preferences for amyloid imaging.

[00:27:43] And with that to kind of explore the patient's motivations for seeking that imaging as well as how the family might view that patients interest in imaging is there a difference of opinion around participation in imaging was that the counsellor might explore what the individual hopes to learn from that testing or was there a family history or a family experience with that kind of driving their interest in such testing into the friendzone to explore that issue in this process overall should hopefully leave the patient and family better informed and help them to understand their own individual circumstances and how they influence or confound their decision. I could go imaging as they kind of describe their reasoning process. Hopefully would also help people to think about the potential outcomes from the chain whether that outcome is positive that there is amyloid deposition in the brain or negative that there isn't enough. Or is it in the middle ground that it's inconclusive and there's not a clear read as whether and when the deposition is occurring. There's also there would be time to discuss the potential ramifications around insurance status or whether employment would be an issue if there were positive findings whether it would influence family dynamics or whether there are emotional or psychological risks to doing the imaging and then are there also positive ramifications to that removal of uncertainty around diagnosis and that are useful for the patient and family. Or is it can it be considered an opportunity to actually plan for the care to consider career changes or to think about supporting the financial planning that needs to be undertaken and to have that useful information for family for the patients children to better understand their own family history and Alzheimer's disease. So then when one coming to the decision it may be important to explore is this is it up to the patient or does it seem that the family has significant influence and that's important to the patient. So all these things get to be explored and pretest counseling and it's especially useful for you know social worker to be in place to kind of guide this discussion.

[00:30:12] Then in post has counseling and follow up this would include delivering the results from imaging and helping patients and the families just understand what the findings mean for them and given their situation. And then what recommendations there might be for a future care planning and participation in preventive treatment trials or should treatment be initiated enough that to consider strategies to cope with any current memory loss or the potential for memory loss. So it seems really that social work practice can really be in a good position to take these rules and the focus changes from family caregivers to really supporting the person with cognitive impairment in their family through this diagnostic process. And to really increase the involvement of individuals with positive amyloid or with cognitive impairment in their own care planning when they're most able to participate. And and another thing that seems really critical with taking on this approach is the multidisciplinary aspect of it that there really would need to be and should continue to be in a collaborative approach to the diagnostic process. So there may be of course a neurologist or a psychiatrist or a geriatrician and nurse practitioners involved in that whole assessment and diagnosis and diagnostic counseling process as well. It seems that social work practice with individuals with Alzheimer's disease is expanding right now. It sounds like it's kind of changing to meet the needs that are developing. And so I'm wondering is there any research underway right now to kind of help inform clinicians practice. So I had the chance to collaborate with Jennifer Swingler at the school of nursing and she's really doing some exciting work around thinking about delivering findings from amyloid imaging especially for people with mild cognitive impairment.

[00:32:14] So she worked with a panel of experts but she convened from neuroimaging and bioethics and research regulation neuropsychology and also a consulting and external researchers who had expertise around diagnostic and results disclosure and through these with support of this panel of experts and external consultants created on diagnostic disclosure protocol as a way to deliver or ideally deliver the results from the White imaging to individuals with MCI and as partners. And so she tested this protocol and sessions with the people with MCI and their families. And we were actually of course in market feedback sessions so we're not yet giving out results. I'm only imaging but you've seen hypothetical scenarios and this protocol presented information on what a diagnosis of NCI means in terms of the risk to develop Alzheimer's disease. And then also the finding whether it was hypothetically positive or negative or inconclusive. And then what that finding meant in terms of the patient and in terms of amyloid deposition was described and based on the findings recommendations for treatment and care will give them as well. This protocol also included providing pictures of pet imaging so that individuals participating in the sessions could see the difference between what a brain with Anwari deposition looks like says I blame the whoredom why that decision. So there is really sort of a tangible visual for people to look at. And Dr. King has found that people really were receptive to receiving these findings and understand the meaning of the findings as well that help them kind of understand the changes that were going on. I think a lot of times we talk about Alzheimer's and it seems kind of abstract when you see the the imaging helps with that.

[00:34:22] It really seemed to him and I think especially Dr. Miller and I was a part of conducting focus groups with some of the participants to just further talk with them about what they took away from the sessions and what recommendations they had to improve them. And that tangibility actually having a picture of a brain that had gone through imaging and that comparison of the brain versus one with MCI or Alzheimer's disease was striking to them really seemed to show was something that was tangible first of all these individuals had heard from a neurologist and the social worker that they had NCI but that was based on was sometimes deemed to be sort of more subjective assessment. So I think definitely as he said that imaging really was critical for the very thing he wanted to add on that research. I think that worked is just showing that people are receptive to these findings. And one other concern can be that people with cognitive impairment may have trouble understanding information like this when it's a wizard and Dr. there was finding that really people understood and had an interest. And it helped them to better explain their diagnosis to other people and to better understand it for themselves. Wow that's great to hear. Now what about you. What are the next steps you're taking in your own research right now. I'm working on my dissertation and I'm interested in looking at those who has some interest in using amyloid imaging technology as far as individuals who come into the Alzheimer's Disease Research Center.

[00:36:07] So I'll be using data from the Alzheimer's Disease Research Center at Pitt to look at what psychosocial factors seem to influence interest in using these diagnostic technologies. So our center is able to track interest in participation in amyloid imaging studies so we have a sense of who does want to participate in these studies whether there are healthy controls with no cognitive impairment or individual tightness within Senai or with Alzheimer's disease and I'll be looking at whether there are differences in demographic characteristics or an neurocognitive status or family history and whether these factors seemed to make a difference in whether people want to participate in amyloid imaging. So I'm looking forward to looking at that data and really what I can find that sounds really interesting. Look forward to hearing what you have to say and what your results show. Anything else you want to add today. Well I just really wanted to say thank you to the Alzheimer's Association and you all have such great information on your website and such an important job in the communities providing support to Samsung. So I just wanted to give a plug for that. Well thank you so much. Thank you for this interview. And for all the work that you do on behalf of people with dementia and their caregivers. Thank you so much for doing the interview. Appreciate it. You've been listening to Amanda Hunsaker discuss the impact of technology on the diagnostics and treatment of Alzheimer's disease 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.

[00:38:09] 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