

Dementia Dialogue; The System Journey, Episode 1

Culture and Communication

Transcript of interview with Ngozi Iroanyah

David - Welcome to Dementia Dialogue. My name is David Harvey. Today we will begin a new series, The System Journey. It is another path described in our overall project, Mapping the Dementia Journey. We appreciate the support of the Geriatric Health Systems Research Group at the University of Waterloo for this series.

Ngozi Iroanyah recounts some of her experiences with parts of the health care system as she supports her father, Felix, who was born in Nigeria and immigrated to Canada in the seventies. Ngozi relates some of the challenges of connecting various health resources together and also some of the unique cultural nuances shared by so many others.

Ngozi was proactive in recognizing the importance of communication, of acting early to seek out and support both her dad and herself.

Thank you very much, Ngozi, for joining our conversation this morning on Dementia Dialogue, where we're exploring the experience of people who have dementia in their lives in terms of their experience with the health care system.

Tell our listeners a little bit about yourself and about your father's experience.

Ngozi - Sure. My name is in Ngozi. I am the adult child of someone who has dementia; my father. He is 81 years young and he is formerly of Nigeria in West Africa, immigrated to Canada in 1972. He was diagnosed with dementia in 2008 and has been utilizing the health care system here in the region of Peel for his dementia related needs.

And so myself and my two brothers are the powers of attorney, my stepmother acts as his caregiver and we all coordinate and cooperate together to make sure that he is safe and comfortable and healthy.

So when he was first diagnosed, it was through his then family doctor at one of the health facilities in Peel, and it was a very significant shock to him. To the family it was also very shocking and painful but the doctor explained to us sort of how he feels the dementia came about with my father.

It was still a sort of monumentous feat to find still some needed services for him; some things were very much underground that you had to sort of dig for.

His experience with the health care system, I want to say because I was there with him that buffered a lot. So I have been working for the health care system. I knew what questions to ask. He began going to the Alzheimer's day program and at first glance, he was adapting well to the program, but as his dementia started to progress and he started to regress back to behaviors and thought patterns from when he was younger (which had very much a cultural component for him) I did notice some disjunction between sort of the things he was doing at the day program and I would be informed of, that I would sort of have to give some context for.

But within the health care system, we were very, very blessed in that he has a great team.

David - Could you describe some kind of act or activity that your father would demonstrate that you connected more to his life in Nigeria and his cultural roots and how that was interpreted or perhaps misinterpreted in the day centre?

Ngozi - It was one incident.

The reason why I know is because I saw him do it with my uncles when I was a child. So they would get together and kind of have like this rousing, kind of jovial kind of gesture in the way that they when they greeted each other.

And then he was doing it at the day care center but I guess to them it seemed aggressive, kind of. So they called me and they said, "Oh your father's doing this and this and this". And I said, "Well, that's how he was raised. That's sort of the cultural thing". And they were like, "Oh!"

I said "Yeah, it's harmless. It's just him being happy to see you type of thing". And I said, "Obviously you wouldn't know that because not everyone's going to know the intricacies of every cultural greeting in the world".

I get that. As people progress and do things that are not common with what's happening now.

Like another instance was when (and this isn't pertaining to him specifically in Nigeria, but it pertains to him as an immigrant from a different country from a different time). So back in the 1950s and 60s, my father was in England. He was studying in England and back then they didn't have the best sanitation system depending upon where you live. So what they would do whenever they would use the washroom, they would use the washroom, but they would dispose of the toilet paper or handkerchiefs or what have you in the wastebasket because they didn't have a sanitation system which to flush things down a toilet. So my father was doing that at the day program and they would call me in a panic and say, "Oh, your father's leaving this in the bathroom, in the wastebasket". And I said, "Well, number one: at least he's disposing of it properly, but he's disposing of it in a way that he connects to from like fifty, sixty years ago and not from what's happening now". And again, they wouldn't know that. So I realized how imperative it was for me to have those lines of communication open so that they can understand what he's doing behavioral wise and I can offer him support him the best way that they can.

David - Yes, yes.

Ngozi - So definitely cultural issues are very, very important.

So in the Nigerian community, as with a lot of other immigrant communities, dementia sort of as a branch of mental health for the aged is kind of seen as it's just part of aging, "Oh, they're older. They get forgetful".

But the actual category of dementia (and all the cognitive and all the body changes and it's more than just memory, as we know), that's not necessarily not that it's not believed, but it's not something that is talked about or seen in the community as prevalent as you would general Canadian society.

David - Am I correct in saying that you were satisfied with how the day centre responded to your intervention?

Ngozi - When it first initially happened, I guess I wanted to be a little bit more surprised that they didn't know but then at the same time, after reflection, very immediate reflection, I knew that how could they know? The staff have to go by the guidelines and policies they're given. The guidelines and policies that they're given are from broader policies that reflect dominant Canadian society. And it's not a right or wrong scenario but it is a scenario, though, that there are gaps, right? And that's where the family obviously steps in and tries to fill those gaps as best they can. But it has to be done in such a way where hopefully there are less gaps, right? And that it's more of a seamless sort of interaction.

But then the challenge is how do you make that happen so everyone feels confident, competent enough to support these patients?

David - How do you think we can support day centre staff and others to serve such a diverse population?

Ngozi - Well, I think and that's the challenge, right? Because there's so many cultures and part of my research at school is just that; how do we help support the support staff? So, having things like cultural competency, cultural safety training for the staff. I have no idea if the day programs have that. I want to say they do, I imagine that they do.

But even more so at the more individual level, I don't see anything wrong with if someone were to call me and say, "OK, Ngozi, these are some things that we notice with your father. Is there like a list you want to give us that the support staff can sort of have something tailored for that particular individual?" And then you can, if need be, you can build from that, right? So if my father is the first Nigerian client, let's say, right? And I say, "OK, well then my father's experience based on his cultural profile; this is what you can expect or what you can help to see and this is what can help him, etc."

And then if they get another Nigerian client, say six months, a year down the road -not that everyone is the same but certainly talking to that client's family and saying, "Hey, what would your loved one need? Can we build off of or build on or change or modify?" And you begin to build a sort of profile.

Yeah, it can even be something as simple as what kind of food makes you feel most safe or happy, right? Or what kind of activities do you like to do that remind you of safety? And that can be a dance they learned when they were, I don't know, 12 or something. Or it could be a certain greeting that they like to have when you walk in.

So there are all these little nuances that can be built into sort of programs from the ground up that can be very reassuring for people and for clients when they come in. It's a very vulnerable time for clients, especially for their families. You know, like an adult daughter, you're seeing your parent go through this transition. And so you're seeing that role reversal happen, right? Where I'm now becoming the parent to my parent. And you have this sense of vulnerability for them, like "I'm going to drop you off at this program. Are you going to be okay? Are they going to understand you? Are they going to receive you? Are they going to accept these differences about you?"

David - Your family use multiple resources. You've mentioned your primary care doctor, a geriatrician, you've had your dad at the day centre. So you've had to call upon different groups to provide you with support. Do you have any thoughts on how these different entities work together or how you wish that they might work a little bit differently? You've made reference to the team. You had a sense of team support, which is really a positive reference. And I wonder if you might explore some of that interagency experience that you've had.

Ngozi - Coordination of care is very important. Oftentimes we operate with our health care in silos, right? So we don't have the family doctor talking to the geriatrician and talking to the therapist. They have their clinical notes sort of going back and forth but largely, we operate in silos and with dementia care it's very important to sort of have that connectivity.

At the team that we have, we do have that. Family doctors do send their notes to geriatrician and they request the notes from this and that so they do have that system going, absolutely.

But, for example, P.S.W.s who come through to support my family in the home, there isn't necessarily reports that go back to the family doctors or to the day programs and this is the change that we've seen, etc, etc.

The day program will call me or give me monthly updates, right? Which then I take back to the family and we share and we sort of strategize around that, what they're seeing. Then I report to the family and if need be, we tell a P.S.W. or we tell the doctors when we go see etc. There does need to be that sort of flow, that constant flow of information. It's sort of wrapping the team around my dad, around the person, right?

It's an inherent feature within our health care system that we do have this flow of information. But the coordination of care, you know, is still something that families very much need to be involved in. And it can get very tiresome and very repetitive. But I do feel that it's something that's essential and needed. And hopefully along the way it gets less repetitive because the system is already setup because that flow has already been there and it's being maintained, right? So what we try to do is we try to go for maintenance of this system as opposed to constantly re-establishing the system, right? So we have our check-in points with the doctor. I'm taking my dad to this geriatrician, I think next month just to sort of check in (he hasn't been there in a year) because she likes to see every six months or yearly checkup. So just "This is what's happening, etc".

We went to see his family doctor yesterday. So, just sort of having that maintenance of this care team. But, admittedly, it took time to get there, right? It wasn't just like you got diagnosed and then within a month, we had this team set up. It took a lot of time and tweaking. Which is the best clinician? Who understands most? Who supports the family as well?

But now that we're in that space, it's a lot of maintenance and it's still very challenging at times, but still very essential. And I always say for any system, it's kind of reciprocal. You get out what you put in, right? So when I say that it's a maintenance sort of endeavor because you're constantly checking in, calling and to keep that stability. And sometimes that stability can still change, right? Because people can move out of the position at the Alzheimer Society or change jobs or what have you. So you're kind of sometimes having to sort of restart that relationship again.

I always tell my friends now whose parents are aging and that if you do notice anything, start immediately. Do not wait until they're like in the middle stage and no one knows what's happening. If you start seeing it, noticing it, start getting things set up now.

Talking about elder care planning within racialized communities, immigrant communities, and a lot of people were saying, like, "We don't have this. We don't think about this". You know? I go, "Yeah, we don't until it's our parents are desperately needing with support. And we're scrambling to figure out what to do".

But also for the caregivers, obviously no one is prepared for this and you don't even know how you feel except to go through it. But whatever supports the caregivers, families, friends, whatever can find, utilize them. Get them in place, get them set up. You know, the Alzheimer Society has these great support groups for people to go and sit once a week and you talk and you commiserate with people because it can feel very isolating.

Reading up on dementia, reading up on what it means to have that transition. I think part for us very much, it was watching my father become the child and us become the parent. And that was very difficult handling the material affairs, the physical affairs and then the sort of emotional mental piece and the dynamic in the family. Which a lot of people that I've spoken to say it's sort of like it crept up on them. You know, you're trying to manage somebody else's physical and mental health and you forget your own and what you're feeling until again, it's like too late and you're like "Oh, wait a minute, I don't I don't feel so well. I feel sad and depressed". And you don't know. You don't know what you don't know. It's a journey for the patients, the person with dementia and it's a journey for the family. It's not a singular journey. It is a parallel journey, right?

David - Thanks very much, Ngozi for your insights.

You will find a link to the Alzheimer Society of Canada on our website, where you can download All About Me, a useful tool for families to help them communicate some of the story of the person who they are supporting and who the service provider is going to be supporting.

More information about The System Journey can also be found on our website, www.dementiadialogue.ca

I mentioned this is part two of our Mapping Project. Part one, Changing and Adapting can also be listened to on our website, at www.dementiadialogue.ca

Our next episode of the Dementia Dialogue will further delve in to the System Journey.

You may wish to visit the website of our partner, the Geriatric Health Research Systems Group at University of Waterloo. The link is on our resource page on the website.

We'd like to hear from you about this or other episodes or about suggestions for new episodes. Write to us at DementiaDialogue@lakeheadu.ca

My name is David Harvey. Until next time, take care.