

Dementia Dialogue; The System Journey, Episode 8

Transitions– Looking Back and Looking Ahead

Transcript of interview with Jim Mann and Jacobi Elliott

David - Today on Dementia Dialogue, we are wrapping up our series, The System Journey, with a conversation with Jim Mann and Jacobi Elliott. In today's episode, we will review some of the key themes that emerged from our previous six episodes in this series.

I first met Jim about 15 years ago when he became the first person with dementia to be a member of the Alzheimer Society of Canada's board. This is one of many firsts. Next month, Jim will be the first person in Canada living with dementia to receive an honorary doctorate. This is from the University of British Columbia and recognizes Jim's unique leadership, not only in British Columbia but at the national level. Jacobi Elliott has a PhD from the University of Waterloo and is an associate researcher with the Geriatric Health Systems Research Group at the university. This group sponsored our series, The Dementia Journey, and today's episode we will review some of the key themes that emerged from our previous episodes in the series. I think you will enjoy the exchange of ideas and insights.

This episode is a bit longer than usual, so let's jump right in.

When we listen to our podcast and listen to the people that participated, we're very appreciative of the effort that people made in stepping forward and engaging in the conversation. A few themes emerged from those conversations. One had to do with a team approach, another had to do with treating the whole person. A third theme had the importance of families being proactive. And then the fourth theme looked at how we could support general practitioners more than perhaps we have done in the past.

I'm wondering, Jim, if you have heard in your conversations and in your own experience about how people with dementia value that concept of a team supporting them as they might get a diagnosis of dementia or as their conditions might change along the dementia journey?

Do you have any thoughts around the theme of team support?

Jim - B.C. has got a number of clinics set up so that there are basically teams within the clinic and from a few people in my support group, I gather that is seen to be quite positive. I have no experience with that. I suspect that for people who receive a diagnosis of dementia really from out of left field, like no one was expecting it, they have no experience with it, never really seen it. So the team approach, I think, might be comforting to them, knowing that once they get the diagnosis within that complex, if you will, there are others who will be able to support them along the way.

David - We sometimes think of diagnosis or health care in too technical a way, and I think it's that idea of human comfort, that somebody will be there if I need to call upon them.

I think it's a very good point. Jacobi, do you have any thoughts on that particular theme?

Jacobi – Yeah, I think the team approach to care is really important when we think about older adults or specifically persons living with dementia, as they move through the health care system, they're going to come in contact with multiple health care providers across

the multiple sectors. And so it's important that everyone is coordinated and integrated to really provide that team based approach to care.

And David, you mentioned in your overview of the theme, the idea of family caregiver involvement on that team. And I think it's really important to highlight that the family caregiver, along with the person living with dementia, they're the only common thread that travels through the health care system, sector to sector, provider to provider. It's really important that the caregiver is considered a part of the team when providing care.

David - I think that's a really important point, the idea of the person with dementia and the family as being the continuous thread across the system. And Jim, I'm thinking of one of our interviews. The fellow, Ron Roberts, spoke about the need for encouragement and guidance to people so that they feel strength and they understand what their role is in managing their health care as they learn that they have dementia. Do you have any thoughts on that kind of concept of building strength in a person with dementia?

Jim - I know that some people will hear the diagnosis or be given the diagnosis and will go home and that's where they stay, basically.

I know a woman in the same city that I live in, got the diagnosis a number of years ago and went home, didn't even tell her daughter, basically went out only when she really had to and otherwise just stayed home. And so it was only because she had read an article from the Alzheimer Society that they had said something about me and something I had done that she thought, "If he can do it, so can I".

And another fellow, no history of Alzheimer's in his family, went home and did what most people do, I guess, is Google and only saw the negative aspects of dementia. And it was only about six months later that he found the video that the city of Vancouver did, Jim's Story, that's on YouTube, that he realized that really there is a life after a diagnosis.

I give you these two illustrations to really show the need for reassurance, really show the diagnosis is only step one. End of life is step whatever, way down the road. There is a journey in between. And that's what so many people and dare I say professionals, as well as individuals, don't fully grasp. They go from diagnosis to you leave the doctor's office and go into long term care. So it's that reassurance that is so very important.

David - I think we've kind of slipped into the theme of the whole person approach. And I'm thinking, Jacobi, if you might want to connect that to the research that you've done in transitions and in primary care in particular and the idea of a whole person approach.

Jacobi - Yeah, I think, Jim, you gave some really great examples of remembering to always have the patient/person living with dementia and the family caregiver at the center of the care and the care plan. So really recognizing what are the individual's goals and preferences. What do they like to do? What things do they still want to continue doing? And how can you build that into their care plan?

And it's as you said, it's not going from diagnosis to long term care. It's considering how to build that care plan around their life so that they still have a good quality of life. And I think to do that, you really need to think about a holistic approach to care. So medicine is one side of things, but the social aspect, psychological aspect as well, and keeping those at the center with the patient.

David - And that really pulls us back to the importance of or the thought of a multidisciplinary approach so that we're not just looking at the physical or the cognitive deficits of a person, but what their strengths are, how they can live their life, different aspects, their mobility, socialization, Jim, as you mentioned.

So there's lots of components that need to be looked at.

Jim - Which reinforces the need for the family to understand as well, because some will take the attitude of, "When you have dementia, you might get lost. So therefore, you're not leaving the house without me" or whatever. And I think that understanding for both that individual who was diagnosed and the family member will go a long way to having a good life, to living a good life.

David - Jacobi, do you have thoughts on the involvement of families and has that emerged in your research as part of the elements of a successful transition, whether it's from normal living to having a diagnosis or having to access community care or long term care?

Jacobi - You know, the role of family caregivers has definitely emerged in our own work in the literature. More recently, of course, due to the Covid-19 pandemic, caregivers play a really, really important role in our health care system and I think sometimes are often overlooked.

You know, there's a stat that indicates that family caregivers save our health care system 31 billion dollars a year. And again, I think they're often overlooked or not included in conversations. And I think we need to recognize that caregivers can play a really important role. It shouldn't be their only role; I mean they're a spouse, the child, a partner, a friend. But they do play a role, a caregiving role. So I think we need to think about what education, Jim, as you said, what education do they need? What supports do caregivers need for themselves? But then what supports do they need to better navigate the health care system, a system that's really confusing and complex.

Jim – And especially because more often than not, they're older.

And so for many people, they've never really dealt with the system, whatever the system is, they've never dealt with it throughout their life to any great degree.

David - The other thing, though, Jim, and I want you to comment on this, is sometimes when families are involved in health care, they tend to replace the voice of the person with dementia as opposed to and it may not be their fault, but it's kind of it's related to ageism, I think, where the voice of the older person, whether or not they've got cognitive impairment, it tends to be overlooked sometimes in our health care conversation.

Do you have any thoughts on how we balance family participation and still preserve the autonomy and voice of a person with dementia?

Jim - How long did you say this podcast is? An Hour?

While we were talking earlier, I kept thinking of the need to listen. And I think that in a lot of cases, sometimes the attitude may well be from the medical side, "I know better. So therefore, I will tell you". I know I've had some people with dementia come and talk to me about their specialists or whatever, not listening to them. And that sort of, "Here's what I think" says the doctor and that's all. There is not a conversation.

And likewise, it's easy if a family member is in, let's say, a doctor's office with the individual with dementia, it becomes, I think, too easy to dominate the conversation. "I saw this happen. I saw that happen" and engage with the doctor and ignore the person with dementia.

I think that in some ways, I go back, David, to the Alzheimer Society a few years ago in the polling, they did that; so a very high percentage of people would be embarrassed if their loved one had dementia and so on.

And so on the caregiver side, you've got all these issues that surround them about dementia and so going into the doctor, it's "You know what? We have ten minutes, we've got ten minutes with the doctor. I'm going to take over. Let's go, here are the issues. Here are the issues". Instead of having the person with dementia sort of ramble a bit.

There's that fine line of we need to deal with issues, but you need to try to maintain control from the person with dementia. And to that I would just add that my mother had Alzheimer's and when I would go to the doctor with her, I would give the doctor a little Word document that I used to call Mum-isms and here's what happened between appointments and that way it's there. You read it, you can deal with it. I'm not going to tell you now. And that allowed for a much better appointment between my mother and the doctor. And I didn't have to be that involved.

David - Yeah, the best use of the time as well.

Jim - That's right.

David – Yeah, Jacobi, do you have any thoughts on that sort of pressure cooker of primary care and time?

Jacobi - Yeah, I just I wanted to comment on, Jim, your comments around balancing person living with dementia speaking for themselves and the balance with the caregivers, I think where possible, because we can look at it from both ends.

Caregivers may also not want to speak up when you're in a room with the person living with dementia about their concerns or how they're feeling. So I think where possible, separating into two different rooms and doing a little bit of deeper dive with the clinician, one-on-one with the family caregiver. How are things going? And then same thing with the person living with dementia and giving them an opportunity to speak and share their stories.

But as you said, it's not currently supported in our primary care structure right now, with the 10 minute appointment time, one condition, one topic, in and out, our system doesn't currently support those engaged conversations.

Jim – No.

I have a problem when I hear and read ministers of health or others talk about, "Well, the family physician should be the point person for the diagnosis and the ongoing care", and I sit back and I think now you've got 10 minutes. So how does a doctor in many cases even get a sense that a person is showing signs of dementia? Like they don't! I don't think they can. I mean, in some instances, the person's going to be all aflutter and may well present.

But that would be, I think, a minority. In a lot of cases, it would seem to me that education plays a huge role for the doctors, the nurses and so on. An education around dementia would give them the confidence to deal with some of these individuals or some of their patients. Even if they are fairly close to them or whatever, if they have a good grounding in dementia and what it means and how to work with your patients with dementia, you're going to feel more confident dealing with that individual.

Whereas right now that's not happening, whether it's the doctors or nurses or whatever. And in fact, at a consultation we did or I participated in last week, a geriatrician said, "Building on the comments shared so far, I really think that the information identified by the research I'm involved in will be so helpful to inform how care providers, how nurses, doctors, pharmacists, etc. can receive better education during the course of their training, as far as medical school and residency it goes, this is still lacking".

It all comes down to, in a lot of cases in my mind, it comes down to education and giving the doctors the confidence to deal with it.

David - And part of that is maybe giving them also some additional resources.

Jim – Tools! Yes. Yes.

David - Tools and time.

Jacobi, what are your thoughts on this issue of support to general practitioners?

Jacobi - This is emerging in our own research in primary care right now and just some research we're doing around frailty, but it's no different; more education and support for primary care providers, general practitioners is definitely needed.

I think this also links back to our first theme around a team approach. So I think general practitioners recognizing when something may be out of scope for them and they need to bring in other individuals, just like you mentioned, in the memory clinic model or First Link, bringing in other supports, other clinicians to assist when we're needed.

Jim - I was in emergency a few years ago, and it was really busy. The nurse would come out from way over here and we were way down here. And so she finally called my name and then said, "Patient only". So my wife and I get up and halfway down she yells again, "Patient only!". So I get up to her and I say, "I have Alzheimer's and my wife needs to be with me". And she looked me up and down and she said, "Well, you look fine". That's why I keep hammering away at the need for education.

David - I want to thank both of you for your quick response and agreement to participate in the conversation.

Jim and Jacobi's conversation validated many of the points raised by our guests as they reflected on their experience living with dementia, being a care partner or as a clinician.

Thanks to the Geriatric Health Research Group at the University of Waterloo for supporting this series and our continuing sponsor, Lakehead University.

Thanks especially to the 11 people who joined this dialogue on the experience of people with dementia and the health care system.

Please help us to reach more people by liking us on Facebook, sending out a tweet or just talking to your friends.

In our next episode, we will have a conversation with Christine Telker, who will be talking about her new book, *For This I Am Grateful*.

You may recall that Christine was a participant in our human rights series, and I'm really looking forward to talking with her again.

In the meantime, take care. My name is David Harvey.