

Dementia Dialogue Season 3, Episode 37

From Research to Action on 2SLGBTQI & Dementia

Transcript of interview by Arne Stinchcombe with Jason Flatt, Ashely Flanagan and Celeste Pang

David - Welcome to another new series on Dementia Dialogue in which we will follow host Arne Stinchcombe in his exploration of the experience of members of the 2SLGBTQI community with dementia.

In this first of four episodes, Arne sketches out some of the issues with Doctors Jason Flatt and Ashley Flanagan and Celeste Pang.

After listening to Jason and Arne, we will be introduced to Celeste and Ashley, who will talk with Arne about their action research project now underway.

Let's listen in.

Arne - Our first guest is Dr. Jason Flatt. Jason is an assistant professor in the Social and Behavioral Health Program at the University of Nevada (Las Vegas) School of Public Health.

Jason is working to better understand the risk and protective factors for Alzheimer's Disease and related dementias among LGBTQ2 people. He has an ongoing research grant from the National Institute on Aging in the USA, looking at the epidemiology of Alzheimer's Disease and related dementias in sexual and gender minority older adults.

Jason, welcome to Dementia Dialogue.

Jason - Thank you so much. I'm excited to be here.

Arne - To start, I'd like to get a sense of what got you interested in dementia among the LGBTQ people?

Jason - Yeah. Well, I have a personal connection. I'm an LGBTQ member but when I was first in graduate school working on my PhD, my grandmother started having some pretty severe cognitive issues.

So she was having issues with like memory and recall. She would even forget that I had called her recently, so I started getting really interested in that. I did a lot of service work during my PhD training where I was doing a friendly visitor program, and I would go meet with an LGBTQ+ senior in their home and spend some time with them and just learn about them. And I got really interested in how, as a gay man, how could I use some of my experiences and knowledge and research to help the community?

So I moved to San Francisco with my husband, and that was a really unique opportunity. I wanted to learn more about like the needs of the aging LGBTQ2 community in San Francisco. And so I did some really unique time where I spent like an hour and a half with seniors in San Francisco interviewing them about their life, their health, their concerns with dementia. From that work, I just realized there was a huge gap and a need to support LGBTQ2 people as they get older. And that really is what's been driving me and doing the work since.

Arne – That’s really interesting. Can you tell us a little bit about some of those concerns that you heard from folks during those interviews?

Jason – Yeah! So a lot of the concerns were really around either knowing they had a family history, right? So they’re like, “Oh, my mother or sister developed dementia”. And so they were concerned, right? Is there some type of hereditary risk for them?

The other piece I learned was most of this, I think almost like ninety percent of the people that I interviewed, were living alone, right? So that was a huge concern for them around even end of life planning. But caregiving; how are they going to do if they did develop dementia? The big concern was like, “How am I going to maintain my life? I don’t want to go into an institutional setting”. That was a big concern.

So we were just really trying to learn about what are some of the strategies they’re using and what kind of services in the community might they be able to access? A lot of it was socially oriented. Food insecurity is a big issue as well as income, right? Everyone’s stretched. And we know that Alzheimer’s Disease is one of the most expensive diseases to manage, right? And so that was a huge concern as well.

Arne - When I talk about LGBTQ older people in the community, they often ask me about risk and are they at an increased risk? What does the research tell us?

Jason - Yeah, so I have some unique research that’s coming out. The first one, it was just published today in the Alzheimer’s and Dementia Journal. It’s focused on subjective cognitive decline in LGBTQ+ people. And so we use data it’s from 2015 through 2018 in the US. The CDC every year does an annual survey where they assess sort of population health. And in this, they were asking people that were age forty-five and older about their concerns with their memory and thinking.

So specifically, they asked people if their memory or thinking was getting worse or they noticed more problems in the past year. And what we found was that LGBTQ people that were forty-five plus were more likely to report that they were having problems with their memory and thinking compared to non-LGBTQ people.

And what added to that is they also said that the memory and thinking problems they were having was also more likely to interfere in their daily lives. So it impacted their ability to work, to do household tasks but even to go and see other people. And it was much higher. Nearly sixty percent of the LGBTQ people with the memory challenges reported that it impacted their daily life compared to less than fifty percent of the non-LGBTQ.

Arne - Yeah, that’s interesting. So is the thinking then that subjective cognitive decline is an indicator, maybe for future dementia risk?

Jason - It might be, yeah. So subjective cognitive decline can be one of the first kind of signs of potential dementia, but it also could be other reasons.

Memory can be impacted by things like depression. They could also be impacted if you had like an infection or some kind of health condition. But then also it could be the signs of dementia that are impacting your memory and thinking. So that’s why we’re concerned. And then even more so is because it’s impacting their daily lives more. So that’s suggesting perhaps it’s more severe.

Arne - I'm wondering about the available data on the number of folks with dementia who identify as LGBTQ. Do we have a sense of the prevalence of dementia within our communities?

Jason - Not really, especially here in the US in the past couple of, the past four years we saw with the administration being led by Republicans, a lot of removal of collection of sexual orientation and gender identity from our national surveys. And then even the surveys that we do have that collect about people's LGBTQ+ identity, they make it optional or some groups can opt to not ask the question. So it makes it very difficult for us to assess.

I'm using data from Northern California. It's Kaiser Permanente, a health system that provides integrated care and sort of tracks all the types of care and diagnoses that people receive. So we are using that data and following people for nearly ten years to look at their risk of developing dementia.

What we're finding right now, and it's important to realize Northern California is a very different place than most places in the US. So a lot better social support structures that are much more focused on helping people and providing resources, as well as some of the more progressive political atmosphere in Northern California. So we didn't find among this group really differences in dementia risk. It was for both around like ten percent risk of developing dementia for LGBTQ and non-LGBTQ. But what we did find that was interesting was a younger age of diagnosis for LGB people. So it was nearly two years earlier that they had a diagnosis. So right there showing you there is a potential concern in that people may get a diagnosis of dementia earlier in the LGB community.

We need more research to understand like, is this a trend that we would see nationally? One really interesting study that came out was back in 2016. There was a study by Christina Dragon that looked at Medicare data from the Center for Medicaid and Medicare Services here in the US. And what they found that was unique was looking at transgender people. But when they looked at their medical record data, they found more diagnoses of dementia for trans people at around eighteen percent, compared to twelve percent for non-trans people. So a six percent increase.

That's concerning as well in terms of current trends, but we need more data. That's the big piece that we're advocating for as we have to ask people about their gender identity, their sex assigned at birth, as well as asking about sexual orientation because we know that LGBTQ people face health disparities. They're more likely to experience chronic conditions than many of their non-LGBTQ counterparts. And then we also see a lot of concerns around mental health, and we really have been linking this to the historical and current experiences of discrimination over their lifetime.

So that's really why we think that we're seeing these health disparities, which then many of them are risk factors for dementia.

Arne - When I talk to clinicians and other researchers, sometimes there's some hesitation to ask about sexual orientation and gender identity. What would you say to those folks?

Jason - Well, I think the big piece is that LGBTQ+ people are not going to be offended if you ask. So that's the first part. In order to make care inclusive for everybody it's important that we ask people about their identities, their backgrounds and make care inclusive, right?

Knowing that if you asked me about my identity and I feel comfortable sharing, there's potential that you're going to build better rapport and trust with me and then my care experience. But also your ability to meet my needs are going to be improved. We've got to collect it. If you don't ask then you can't help, right? And you also will likely lose clients or customers because we want to go somewhere where we're valued and respected.

Arne - So I think that respect is such a big thing. Is there anything else that you would recommend in terms of how to best support LGBTQ2 persons with dementia and their caregivers?

Jason - Yeah. Well, I think the last piece is really around caregiving. So much like I said where the community often is isolated, well, this doesn't end when you become a caregiver, right? And even though you're caring for someone else and trying to help coordinate care and keep them in their home and make sure their needs are met, often it can be a really lonely experience. And caregivers experience discrimination, as well as fear that the person they're caring for will experience discrimination when they go to access services.

So we need to do a lot more also to make sure until we find a cure for dementia, we need to be making sure we're equipping caregivers with the support they need, people living with dementia, the support that they need and really changing the way our systems work with older people, but especially LGBTQ+ people.

This is just going to become more of an issue as we see the shift in our population getting older and older, right? And so if we don't have plans in place to help people that are caregiving...I know the Alzheimer's Association puts out, like it's like something like billions of dollars of unpaid care that caregivers provide. And we know that those burdens lead to health problems for caregivers who might even develop dementia. So we need to really bolster services for caregivers and especially LGBTQ caregivers.

Arne - Jason, I appreciate you being with us today, thank you.

Jason - Yeah, my pleasure.

Arne - Our next guests are working on a research project focused on 2SLGBTQI persons living with dementia and their unpaid carers in Canada.

Ashley Flanagan is a research fellow in diversity and aging at the National Institute on Aging in Toronto. Ashley's research focuses on 2SLGBTQI persons and aging, with the goal of advancing comprehensive health and wellness policy, programs and services for older adults with diverse gender and sexual identities.

Celeste Pang is a socio-cultural and medical anthropologist and holds a research appointment as a senior research officer 2SLGBTQI health, aging and housing at Egale Canada. Egale is a leading national organization for 2SLGBTQI people and issues. Celeste's work aims to advance critical conversations about aging, care, disability and gender and gender nonconformity in later life.

I'd like to welcome you both to the podcast.

To start, I'm really excited to learn about your research project, but before we get there, I'd like to get a sense of what led to this research project.

Celeste Absolutely. So this research project was an outgrowth of ongoing research, advocacy and education work at Egale Canada focused on 2SLGBTQI aging issues. So it grew out of an interest in how we can better support and build that foundational knowledge about how to better support the communities that we serve.

It is a multi-phase project for which the research is the foundation and to do the research, Egale partnered with the National Institute on Aging and Ashley and myself are leading the research.

Arne - Can you tell us a little bit more about the project, some of the methods, what you're hoping to find?

Ashley - Our approach to this project is two phases.

The first phase we recruited folks to participate in focus groups, which happened online. So we ran focus groups with 2SLGBTQI folks living with dementia. And then we had separate and simultaneous focus groups with unpaid carers of folks who are 2SLGBTQI and living with dementia.

So they didn't necessarily have to be in a caregiver dyad. We had folks who came to the project who had past caregiving experience and also people who are in the thick of it at the moment.

So we have that. The focus groups wrapped up in the spring. In the middle was of analysis with those. And then coming up, we have a consultation event where we're going to bring together the participants from the focus groups and also stakeholders in dementia care in 2SLGBTQI aging and together into the same space to kind of brainstorm and think of ways that we can take what we found in our focus groups and move it forward. And what we can do to kind of reach the most people and have the most impact that we can know.

Arne - You're in the middle of data analysis. Can you share a little bit about what you're hearing from folks? What are some of their concerns or some of their challenges?

Celeste - So one key finding thus far that's come through quite clearly is that for carers of 2SLGBTQI people living with dementia, they come to this care work and engagement from various pathways. So we met with people who were caring for siblings, caring for aunts, caring for spouses, as well as people who had been brought into this orbit of care for community members or people who had previously been more distant friends.

So the importance of community of different forms of queer kinship in supporting people through their journeys with dementia is definitely one of the most striking findings thus far.

Ashley - And then in addition to that kind of the orbit of care, folks that are kind of immersed in it talked about being quite isolating and then talked about the focus groups as this first opportunity that they had to share their experiences and hear about experiences from folks who are also caring with and for 2SLGBTQI people living with dementia and also talking to someone else who is also walking the journey of living with dementia as someone who is 2SLGBTQ I.

So having that focus group experience kind of really turned into those really powerful conversation between people and the offering of support. And what came out of that is

kind of this really intense desire for ongoing conversations and whether it's a support group or whether it's organizations kind of take up that call and provide these spaces for folks to come together and share that's kind of outside of whether it's dementia specific group or 2SLGBTQI aging group, but having this really intersectional space for people to share.

Arne - When I talk to folks in the community, sometimes I hear that the perception that dementia is the same for majority folks as it might be for minority folks like queer people, what do you say to that?

Celeste - I think from the conversations that we had there are certainly many similarities and also key differences.

In one sense, with dementia comes a lot of change for people themselves, for those in their lives. One particularity with 2SLGBTQI communities we have been finding and have each found in prior work, are these transformations around, and if gender expression also transformations around sexual identity and relationships, even within couples, comes home in particular ways. This can be brought to the fore when people are interacting with care systems and worried about whether their relationships will be recognized when they're seeking to enter different kinds of dementia support spaces and even their close others are not recognizing them in the same ways. There is particularity to that that is, I think, distinct than, say, a heteronormative couple form of people going through this journey.

Ashley - I think you really nailed it there. Just that sense of whether it's kind of this feeling of an erasure of a relationship. So we've had folks talk about and that is exactly what Celeste just said, but that there's this sense when you're interacting in a support space and people make assumptions about your relationship that try and fit you within kind of this very heteronormative relationship frame where it's either sister or sibling or parent or a parental relationship if there is if there is an age gap in the relationship, that kind of erases the actual relationship in a way that tries to fit the relationship into this kind of heteronormative space that leaves people feeling unseen and unheard and not as supported as they had hoped kind of coming into that space.

Celeste - You know 2SLGBTQI folks have by necessity and through creativity formed many different kinds of relationships over life and have also had to provide care in very challenging circumstances in the past, for example, around HIV. And people are definitely bringing a lot of their expertise, their skills, their lived and embodied knowledge towards what it means and what it can look like to experienced dementia either as the person themselves or those around them.

So I think there is also not necessarily unique, but particular creativity and resourcefulness that our communities have been sharing with us.

Arne - I'm wondering if there are little pieces of sort of positivity that you might be able to kind of bring out of those findings that might come to mind right now?

Celeste - It's definitely and I don't know if you would call this a positive, but among some of the participants who are more active in advocacy type initiatives or in sharing knowledge about living with and caring for a person living with dementia, there's some space of opportunity has been provided to share and to be placed in that position of someone with

knowledge, with some capacity to mentor. Definitely desire to mentor if those spaces aren't open.

So my take on that question is we definitely identified a lot of notes of potential, but there really needs to be more social and structural support for these notes of potential in what occurs to really be tapped into and to be supported for the betterment of everyone involved.

Arne – I'm wondering, based on the research findings, if you can speak a little bit to some of the opportunities for change, either within formalized systems of care or informal systems that exist within the community.

Ashley - One of the biggest things that folks were talking about and it came through time and time again in the focus groups, was this idea about long term care and that people are thinking forward to the future of when they may not be able to support themselves or support their loved ones in that relationship and what kind of that greater level of assistance will look like, whether it's a long term care home or whether it's home care or whether it's some sort of assisted living and having conversations about what their needs are around that.

And I think that what is coming out of those conversations and moving forward is this need for more education, more advocacy around lived experiences of folks who are 2SLGBTQI and on a more broad level and working with folks who are providing care to provide it in a way that is the most appropriate, is the most affirming and recognizes lived experiences that people are bringing with them into care contexts I think, is a big one that folks were talking about, if we're thinking more long term into that care relationship there.

Celeste - Yeah, I would also emphasize that the project is focused specifically on unpaid carers on the end of caregiving and definitely what came through, not so much in explicit statements, but in what we can interpret and think through as analysts and researchers, is the very strong need for greater support for carers in general. If this is caregiving leave, if this is more home care support, more support services, perhaps form of respite care. This is certainly not unique to 2SLGBTQI communities, but it is certainly called for, certainly desired and there's definitely a need.

Arne - I'm just wondering if you came across any promising resources that exist in Canada or best practices that we might be able to point folks to, should they be interested in more support?

Ashley - Right now, there seems to be a lot of work being done in this area, but I think in the future there will be a lot more, I should say, resources out there for folks.

But as it stands right now, we didn't find anything that people could turn to in this moment who are living community. There are a number of resources out there and are being developed also for kind of long term care; more paid support and supporting folks in that way. But in terms of kind of that unpaid aspect, not so much at the moment.

Celeste - And definitely this was part of the impetus of this project to begin with, was this enormous gap. There seems to be an energy and a lot in the works. In the future, for example, this research will inform some e-modules that we will develop. Also along the way, we've been trying very hard as the researchers to make connections that makes sense in terms of an end goal.

This kind of research with communities who are precariously positioned, who have historically and continue to have very fraught relationships with health care systems, with different social institutions, our aim is not to create yet another population to figure out how to intervene in, but to learn what people are seeking and what they need to be supported on terms that are more their own.

Arne - I want to thank both of you for taking the time to share your work with me and with our listeners. I've learned a lot. Thanks.

Celeste - Thank you.

Ashley - Thank you.

David - Thanks to Jason, Celeste and Ashley and of course, Arne for scoping out some of the issues in our upcoming episodes.

I think it is fair to say that COVID 19 has heightened our collective awareness of how different economic, social and cultural factors affect a person's health. This awareness is beginning to influence our thinking in various fields, including dementia, such as this life as a 2SLGBTQI person, place one at greater risk than being in the dominant community or are services equally available to them.

Since we are interweaving our arts and 2SLGBTQI series, our next episode will feature co-host Cynthia Huling Hummel joining Lisa Loiselle on the subject of dementia and the expressive arts. Please join us.

We want to hear from you, our listeners, about how we can improve our podcast, make it more accessible to people and reach more listeners. To do this, we're hosting three separate focus groups in November. Please consider joining one of them. The groups will be professionally facilitated and will last no longer than an hour. For more information, please write to dementia.dialogue@lakeheadu.ca
We would love to hear from you.

Thanks to the Center for Research and Education on Aging and Health at Lakehead University, our institutional partner into the Public Health Agency of Canada for its financial support.

My name is David Harvey.