

Dementia Dialogue; Human Rights Series, Episode 5

Dementia, Stigma and Action

Transcript of interview with Alisa Grigorovich, Pia Kontos and Phyllis Fehr

David - I recently subscribed to a newsletter, theconversation.ca, which publishes essays by Canadian academics on issues of societal importance across several fields. In August, I read Covid-19 Stigma and the Scandalous Neglect of People Living with Dementia, and it hit home. At Dementia Dialogue we had been thinking of an episode on stigma as another part of our human rights series. I reached out to Alisa Grigorovich, who reads the essay and Pia Kontos its coauthor, and also to Phyllis Fehr, a member of our editorial board and a dementia activist.

Pia and Phyllis join in conversation after Alisa reads the essay.

Alisa - Covid-19 Stigma and the Scandalous Neglect of People Living with Dementia, by Alisa Grigorovich and Pia Kontos

Over 80 per cent of Canada's COVID-related deaths are associated with nursing homes, with the majority of them being older persons living with dementia.

Moreover, recent international research suggests that COVID-19 public health restrictions have contributed to tens of thousands of additional deaths among people living with dementia in nursing home settings as a result of barriers in access to care and social isolation.

This is a national atrocity, and worse, one largely of our own making.

The role of stigma

From the beginning of the pandemic, what has been striking for us is how little mention there has been in the media regarding the role of stigma in shaping care practices and public health response strategies to COVID-19.

We are critical social scientists with expertise in dementia, ethics, and long-term care. Collectively our work is motivated by a shared concern about how stigma associated with dementia consistently enables and legitimizes restrictions on the freedom of individuals living with dementia, and denies them opportunities to pursue life-enhancing relationships and activities.

We have traced this stigma to two cultural narratives about dementia: with memory loss there is a total erasure of the self; and the medicalization of memory loss, which reduces nursing home care to supporting basic physical safety and comfort. Together these narratives perpetuate a collective representation of persons living with dementia as "non-persons."

This highlights the inherent ableism and ageism that dehumanizes and demarcates the lives of people living with dementia as disposable. Critique of this representation of people living with dementia as disposable must be a central part of public discussion and debate. Without that critical assessment, reform strategies are doomed to fall short of achieving the radical change that is needed.

Conditions well-suited to COVID-19

The toll of COVID-19 in Canada's long-term care homes is the result of structural conditions that have long been identified by researchers in the field of aging studies. COVID-19 has efficiently exploited these conditions, most notably the heavy reliance of nursing homes on a temporary and casual workforce, low staffing levels and inadequate care supplies.

Analyses of these structural conditions have featured prominently in media coverage and related reform strategies including: non-profit public provision; permanent employment and benefits for providers; minimum provider-resident ratios and integrating long-term care into the federal health portfolio.

While such analyses and reform strategies are critically important and are not to be disputed — indeed, we too have argued the need to address these structural conditions — our analysis pushes further.

A new ethic of dementia care

To achieve real transformation, we need system-level efforts to improve structural conditions in nursing homes, but we also need a new ethic of dementia care.

Specifically, we need an ethic that challenges stigma by broadening the duty of care to include fully supporting the capacity of individuals living with dementia for creativity, imagination and other positive potentialities. This would require the provision of life-enriching opportunities for persons living with dementia, and the support of their engagement with social life to the fullest extent possible.

This is consistent with Canada's National Dementia Strategy to eliminate stigma and create dementia-inclusive communities. It is a call for creative, visionary and transformative reform at a time of moral urgency.

It is our argument that a new ethic of care is urgently needed to ensure that the goals and standards of dementia care focus on supporting the life enrichment of persons living with dementia. This requires a model that draws on the fields and sub-fields of human rights, citizenship, political economy, feminist care ethics and "embodiment," a field that aims to understand bodily experiences as ways of knowing.

This model is well suited to address the stigma associated with dementia and the structural inadequacies of nursing homes that are responsible for the neglect and harms that we have seen in this pandemic, as well as before COVID-19.

The model also recognizes that our bodies — our capacities, senses and socio-cultural dispositions — are central to self-expression and to our engagement with the world. With cognitive impairment, embodied self-expression becomes the primary means of communication and as such it is a matter of social justice. Consequently, this model holds states responsible for supporting these rights in practice through regulation and redistribution of social and economic resources.

We hope that social and health scientists, gerontologists, ethicists, policy-makers and care providers who are equally committed to re-visioning nursing home care will agree, and devote resources to this collective effort. It's time for a new ethic of care to replace the stigma of dementia.

David - Thanks very much, Phyllis and Pia, for agreeing to join this conversation and Pia for you and your colleague Alisa to lend a reading of the essay to form part of this podcast. Again, my appreciation. And then, Phyllis, I will ask you if you might comment on your first thoughts, having read the essay and having just listened to it.

Phyllis - You know what? I was absolutely thrilled when I read the essay for the first time, because for years what I have been saying was included in that essay. So some of the areas that were really highly important to me that were mentioned were ableism and the ageism that dehumanizes and denigrates the lives of people living with dementia as disposable. Well, you know what? I've watched my grandmother go through this in the sixties. And when she was diagnosed, she was brought home to sit and die, never spoken about again. Then my mother's in the eighties and nineties. And that's why when I got diagnosed, I says, "I'm not going to take this sitting down. I'm going to cause waves".

And so when I read this, it was so highly important to me and it hit home in so many different ways. You know, we're not just a brain walking around. We're more than that. We're not just a person living with Alzheimer's. We come with all kinds of life experience. We come with all kinds of knowledge. And just because we have been diagnosed with dementia does not negate the fact, that we lose our intelligence because we don't. We may have trouble accessing it, but it's still there.

The only thing that really pulled kind of a little bit of a string, was in the one paragraph where you said that, "We hope that social and health sciences, gerontologist, ethicists, policymakers and care providers who are equally committed to revision nursing home care will agree". And I think that the only reason that kind of pulled at me with because you included care partners and that type of stuff, but never included somebody living with the disease who can be so vital in giving pertinent information.

David – Pia, I'm wondering if you might want to just comment on what Phyllis said, particularly the last point, I suppose.

Pia - Well, let me first say that I agree with Phyllis, that stigma is a terribly important issue. People living with dementia come to be defined solely through their disease and the stigma that's associated with it. It allocates the person to a lower social status. It results in their marginalization and leads to avoidance of social interactions and isolation, feelings of shame and inadequacy and stigma also extends to family. I mean what's been termed courtesy stigma and has been linked to negative emotional outcomes, reduced help seeking increased care stress. So it really poses a significant barrier to the social inclusion of persons living with dementia and their families and negatively affects health, well-being and quality of life.

I take your point, Phyllis, and really that was a gross oversight on our part. We should have mentioned the importance of including people living with dementia. Absolutely. So it certainly wasn't our intention to leave people living with dementia out of this important dialog.

David - Phyllis, you mentioned your grandmother, your mother. I'm wondering if you might just share with our listeners a couple of examples of the way you've experienced stigma.

Phyllis - The first incidence I will talk about is when I was getting diagnosed. So going to the family doctor, they don't even want to look at it because you've got to remember, when I started seeing symptoms, I was only forty eight years old. So they don't really want to look at it.

When I finally got through the whole system and went to the gerontologist and she did all the testing and my husband and I went in to get the results, I honestly had to sit there and bite my tongue because I was never looked at, I was never spoken to. I felt like my personhood had been ripped away from me and that now that I have it written on paper, that I have dementia, that I can't understand a word she's saying. And that's why she spoke to my husband.

So that really did affect me. And it took me, I'd say, a good year to two years to get over that and to get in my head that know this isn't right. I can still do these things. I just have to do them differently.

David - Phyllis, you've gone on from that experience of being diagnosed and shutting down for a while, and then you've become pretty, a very effective spokesperson for people with dementia. I'm wondering if you might describe some of your activity and some of your involvement as a dementia activist.

Phyllis - I will say it started off here in Hamilton, I joined the Alzheimer Society here in Hamilton. In my mind, not enough was being done. After that I got involved with the Ontario Dementia Advisory Group, which was a very active group on making change for people living with dementia, here in Ontario. We worked on the Ontario Dementia Strategy.

I've also joined international groups and with some of the international groups I've spoken at the World Health Organization. I've spoken at the United Nations. And when Canada reported on their human rights surrounding dementia, I was there and was able to get dementia included in the name because working on the Canadian dementia strategy.

I also do a lot of human rights work and I travel all over the world really to speak at different conferences on human rights for people living with dementia and what it's like just to live with it every day.

For people living with dementia, and I've heard this multiple times because I run an online support group for people living with dementia through Dementia Alliance International, and what I found was when I first attended my first support group, that was all just people living with dementia, I felt at home. I didn't feel like I had a problem. I didn't feel any different than anybody else sitting at that table.

And the other piece is when we're still involved in research, because some of us can still do that stuff, that also helps. It also makes you feel like, "Oh, my goodness, I can still do this". It gives you that positive boost that you need rather than sitting on the couch and going, "Oh, I have dementia, I can't do anything".

Pia - Sure, I'm happy to be, very pleased to have this opportunity to talk about Reimagining Dementia; A Creative Coalition for Justice. When we saw that over 80 percent of Canada's Covid related deaths were associated with nursing homes, with the majority of them being persons living with dementia, we were very angry and felt a need to take immediate action. And that anger quickly turned to outrage, given how little mention there's been regarding the role of stigma in shaping care practices and also the public health response strategies to Covid, which are having a profound impact on people living with dementia and their care partners.

So the issue of stigma is highly complex and achieving the kind of radical change that's needed to address it is also very complex. And so we need system level efforts to improve the structural conditions of care. And we also need an ethic that challenges stigma by broadening the duty of care to include fully supporting the capacity of people living with dementia for creativity, imagination and other positive potentialities.

I think that requires education. It requires lobbying. It requires innovation at every level of society. And there is no one organization that can achieve that alone. So we felt that a coalition is what's needed to forge strategic and tactical alliances across the globe with people living with dementia, family and community members, health care practitioners, advocates, artists, academics, policy figures and many others, really to work collaboratively to challenge stigma associated with dementia and to mobilize the practices and political processes that are needed, I think, to finally achieve a humanizing vision of care and support that promotes inclusion and relationality and the possibility of growth for everyone living with and who are impacted by dementia.

So something that is unique about this coalition is our commitment to the arts as an innovative way to address the social injustices that we've been discussing here. The arts are increasingly advocated for education to promote personal and social transformation.

And so social justice oriented theater is an example that's proving to be really effective, an effective way to challenge stigma and to raise awareness about the importance of relationships and relational caring. And so we strongly believe that the arts are a really powerful means of challenging stigma and supporting the humanity of people living with dementia.

Phyllis - David, can I just read something I read on Facebook the other day, and I think it's kind of pertinent to what we're talking about. It's from Ian Kramer, who is part of the LEAD Coalition, and it says, don't dare call it denial when people choose to live fully with dementia. Call it courage. Call it optimism. Call it defiance or just call it living.

David - Well, I'd like to thank the two of you for this conversation. I think it's been very rich. Thanks very much.

Stigma is the antithesis of human rights and imposes false limitations on individuals and communities.

I'm encouraged when I talk with people like Phyllis and Pia and Alisa. Their efforts are making a difference and each of us can do our part. Reimagining Dementia is a project that Pia Kontos is active in. They are seeking to create a space for dialogue to lead strategic actions, actions led by people living with dementia first and foremost in partnership with family and professional care partners and others who are committed to culture change.

Our Resource Page has a link to the article read today, as well as contact information for Reimagining Dementia.

Please get in touch with us and tell us your reaction to this program or other episodes that you've listened to. You can contact us via Twitter, Facebook or by writing to us at dementiadialogue@lakeheadu.ca

Thanks to our sponsor, the Center for Education and Research on Aging and Health at Lakehead University.

Please listen to our next episode, where we will go to Saskatchewan and learn more about the system journey in a small Saskatchewan community.

Thank you. My name is David Harvey.