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Sheridan Conty

sheridanconty@cunet.carleton.ca
Carleton University

Abstract

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Institutional Care for our Elders: A Conversation with Dr. Ellen Badone

Sheridan Conty

sheridanconty@cunet.carleton.ca
Carleton University

Dr. Badone holds a PhD in anthropology from the University of California, Berkeley, and is Professor Emerita in the departments of Anthropology and Religious Studies at McMaster University. She has spent her career as an anthropologist studying how people construct meaning in the face of death and dying. Her initial research focus was on the social and cultural context of aging, dying, and death in Brittany, France. For her dissertation and first book, she studied religious practices relating to death and ideas about the afterlife. When we sat down for our interview, Dr. Badone explained to me that although she might have originally described herself as a folklorist, she now identifies her work as being part of the realm of medical anthropology. Most recently, she has written about the state of Ontario's Long-Term Care (LTC) system, particularly in relation to the impacts of the COVID-19 pandemic (Badone 2021). When I asked her how she transitioned from studying death and dying in Brittany to studying LTC in Ontario, she reflected that it was somewhat natural, suggesting that one naturally compares things in one part of the world to another.

> I was sort of comparing my experience with my family in Ontario, with people that I knew, with families in Brittany. And looking at how the things I had been interested in, like care for the elderly, how that played out here… and my own experience of looking after my parents contributed to that as well. Plus, I have power of attorney for one of my former professors from when I was an undergrad at the University of Toronto, and she's now in Long-Term Care.

As such, Dr. Badone turned her focus to how those LTC residents, and their significant others, make meaning out of their experiences with death and dying in pandemic times. Previous editions of *Aging Talks* have explored the interdisciplinary and practical applications of research on aging and the life course (Maripuu 2023; Jesperson 2021). Dr. Badone and I share this interest and discussed it in relation to another shared interest: the study of aging and elder care systems in Ontario. In Ontario, eldercare, and LTC in particular, is one of the most regulated sectors, so much so that many of my research participants describe it as "over" or "hyper" regulated. At the same time, Ontario, as a Canadian province, is responsible for the management and delivery of universal and public healthcare. I believe there may be something distinctive about Ontario's particular combination of universal healthcare and the "hyper-regulation" of its elder care spaces, and that inquiry into this combination of forces may lead to fruitful insights into the practical and/or policy applications of research on aging.

When I asked Dr. Badone about how access to universal healthcare may impact the study of aging in Canada, she responded, "Well, certainly in my own case, I wasn't aware that LTC wasn't covered by the Canada Health Act until I started doing this research. And I think… this may be a part of a broader public lack of knowledge." As Dr. Badone suggests, many Canadians are unaware that residence in LTC facilities is not fully covered by universal healthcare. She went on to explain that she believes that there is a sense among Canadians that when it comes to healthcare, we do things better than our American

counterparts. Popular conception may suggest that because of our publicly funded healthcare system, Canadians do not experience situations in which they cannot afford, or cannot access, potentially life-altering healthcare services. Dr. Badone asserted, "I think we close our eyes to some of the problems. Unless we encounter them through our own families or our own experience, we aren't aware that there are people falling through the cracks all the time, you know?" She also went on to say that this may have also been part of why the public was so shocked and outraged when the COVID-19 pandemic hit LTC institutions as hard as it did. Notably, throughout the first, second, and third waves of the pandemic, LTC residents accounted for 43% of COVID-19 deaths across Canada (Canadian Institute for Health Information 2021).

As scholars who study aging and eldercare, many of us may come up against regulatory systems, and their corresponding funding systems, that are deeply layered and difficult to navigate. This is the case in Ontario, where there is no single, clear-cut source that explains how Ontario's LTC system is organized, regulated, and funded. When I asked Dr. Badone how she managed to get a grasp of the structure of LTC in Ontario, she responded that she really had to piece things together herself, drawing from academic articles, government reports, reports from public organizations, and articles written by journalists. In particular, she turned to the websites of a variety of Ontario ministries, the Ontario LTC Association, the Ontario Health Coalition, Ontario's COVID-19 science table, and academic inquiries into the Canada Health Act.

Dr. Badone suggested that the hyper-regulation we see in Ontario's LTC sector is, to a degree, part and parcel of institutionalized care. Any institutional care setting, be that schools, daycare, hospitals, or LTC, if publicly monitored, will have regulations. She highlighted a paradox that she sees in LTC:

> Our society seems to want institutionalized care for the elderly. Or at least seems to need it. Or maybe we have an uneasy relationship with it, because on the one hand, I think there's a recognition on the part of families that they can't cope with the demands of care for elders with dementia and other severe health challenges. Yet, what we want is not the institutional context. It's hard however to come up with a solution that meets the level of need. You know, I'm sort of constantly surprised when I see that there are over 50,000 people in LTC, in Ontario. That's a lot of people.

It's important to note here that in addition to the number of people currently living in LTC, there is a four-to-five-year waitlist for those seeking to get into LTC. Dr. Badone suggested the way Canadian society views aging and elders underlies our desire to have long-term care institutions, where aging and its impact are hidden from society at large. I surmise that perhaps the regulatory burden experienced by those living and working in LTC is also linked to the way that Canadian society sees aging and treats elders, pointing towards larger philosophical issues behind the problem of regulation. Significantly, and as already noted, the hyper-regulation of the LTC sector did not stop the disasters that occurred in LTC during the COVID-19 pandemic.

When considering elder care systems that are hyper-regulated, questions arise about how we can practically apply research findings with the aim of having a positive impact on these systems. These questions many be pertinent to all those who study aging. I often find myself thinking about how my research might be used to better the working conditions of those employed in institutionalized elder care, and better the quality of care received by those living in institutional elder care settings. By extension, I also think about how my research could serve to improve the experiences of others who

have relationships with those working and living in institutionalized care settings. For instance, relatives or close friends of elders and care workers, who care for those entangled in the LTC system. This is something that many of my research participants inquire about when we sit down to talk: how is my research going to help? When I asked Dr. Badone her thoughts on this, she responded, "I'm also really concerned about public policy and the equitable distribution of public healthcare. The frustrating thing is it's so hard, I find, from within academia, to make a difference in the policy world." Indeed, it can be incredibly difficult to access the networks of people who influence policy, or who write policy.

Dr. Badone suggested that one avenue for effecting change is to align oneself with a public organization that is already doing important research and lobbying for regulatory changes. She identified the Ontario Health Coalition as one such organization, but she also acknowledged that organizations like the Ontario Health Coalition are still themselves *outsiders* to the regulatory system. My own dissertation fieldwork has provided me with the opportunity to learn from leadership staff in LTC institutions. On numerous occasions I have been told by leadership staff that their understanding is that when new legislation is put in place, "public expectations," as reflected by the lobbying of public organizations, are taken into consideration. And yet, there is still a disconnect here between the lobbying of public organizations, legislation, regulation, policy, and the everyday outcomes of these forces. Take for instance the "Fixing Long-Term Care Act" (FLTCA) passed by the Ontario legislature in the 2021. The FLTCA states that four hours of direct care will be provided daily to every LTC resident. While more hours of direct care a day has been a primary concern voiced by LTC residents and their significant others, there are several factors that limit the effectiveness and achievability of this Act and its corresponding regulations. One of these factors is the current staffing crisis which spans across all healthcare sectors, but which is perhaps most apparent in the elder care sector. Without adequate staffing levels, it is impossible to achieve four hours of direct care a day for LTC residents. When the FLTCA was passed, residents received an average of one and a half hours of direct care a day. Although the government has committed to contributing over twenty-million dollars to support the FLTCA, only a small portion of this will be felt by frontline staff, who arguably make the largest impact on the quality of care in LTC. As Dr. Badone reasoned, better renumeration, and a revaluation of how our society values elders and those in proximity to them would go a long way to invigorate the workforce of frontline staff in LTC institutions.

What I will be taking away from my conversation with Dr. Badone is that while the question of how to practically apply research to influence policy may not be one that is easy to answer, it is nevertheless important. As scholars, we may do well to think creatively when it comes to these kinds of endeavours. This discussion also raises questions about where the future of aging studies may be headed. The study of aging is subject to change as popular imagining of what it means to age and require care change as well. When asked about the future of aging studies, Dr. Badone highlighted its unknown nature, pointing towards the impacts that "transhumanist" or "immortalist" movements might have not only on how we study aging, but also on how we think about it as a society. As scholars of aging have explored, a small but influential minority of people in the West seem to be chasing the goal of overcoming mortality using technologies such as robots, cryogenics, and even blood transfusions (Huberman 2022). As only one of many possible examples, how might these kinds of practices influence how we experience aging and whether it is seen as negative, as an illness to be overcome? And how might this in turn influence regulation and policy around elder care?

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