Vulnerability, social triage and the COVID-19 pandemic

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Abstract

If we are concerned about managing pandemics better, we need to secure and ameliorate the lives of all vulnerable people, including those with disabilities, people of colour, immigrants, seniors, and low-income essential workers who have been disproportionately affected by the coronavirus disease 2019 (COVID-19) pandemic. Before the pandemic even started, these groups had been "triaged" away from care by their social and economic circumstances, where structural features of their lives made them more susceptible to the physical dangers of COVID-19. This commentary article argues that the social determinants of health (SDOH) must be taken into account to create better living and working conditions for our most vulnerable citizens. By adopting a macroscopic perspective that re-examines cultural biases, safety regulations, labour laws, building codes, urban-planning and socio-economic policies, our society will be better equipped to weather global pandemics or other crises in the future.

Introduction

The first wave of the new coronavirus has exposed our biases towards vulnerable people and has brought to light our shortcomings in how we accommodate people who appear to be different. Increased vulnerability during this pandemic arises not only from innate physical characteristics, such as a weakened immune system, obesity, and heart disease, but also from policy decisions and social behaviours that alienate certain individuals from the rest of the population and have made them psychologically, physically, socially and economically susceptible to this virus. Disabled populations have borne a significant burden not only from the disease but also from the public health and socioeconomic responses to the pandemic. Additionally, the elderly population suffered terribly from the coronavirus disease in many countries including Canada;[1] seniors died at home as well as in long term care facilities, often isolated and alone. Racial and ethnic minorities, and those with lower incomes, have experienced noticeably higher infection and mortality rates due to the coronavirus disease 2019 (COVID-19).[2,3] These individuals tended to be part of the "essential" workforce, which not only cared for the ill, but also picked vegetables and fruit, cleaned public and private spaces, transported goods and re-stocked retail shelves. Across many differing jurisdictions, these workers fell prey to the coronavirus in highly disproportionate numbers.[4] While triage protocols were drafted or implemented in response to the extraordinary demands of COVID-19 on health care systems – recall the "who gets a ventilator debate" at the beginning of the global pandemic – we argue that pre-existing social, physical and economic conditions had already largely triaged many people away from care by creating contexts in which viral transmission could thrive and kill. The COVID-19 pandemic teaches us once again that everyone's health, but most particularly that of the physically vulnerable and socio-economically disadvantaged, depends upon more than just medicine, it depends on social factors.

Social Determinants of Health (SDOH)

Experts have shown that access to housing, green space, playgrounds, safe neighbourhoods, transportation, well-functioning schools, fresh food, and employment improves overall health.[5] Although many recognize and try to address these SDOH, acting on this knowledge proves to be difficult.[6] Many communities do not have adequate capacity to address these determinants to undertake ameliorative social policies. Moreover, addressing SDOH requires coordination between a variety of sectors with separate funding streams, where investments in one siloed sector may accrue savings in an adjacent one, and so data collection and calculating the impacts of investment is difficult. For example, a government agency which funds social housing will not likely propose or assess any benchmarks with regard to the physical or mental health of residents, and so it remains unaware of the health impacts that its bricks and mortar projects might engender.

The Invisibility And Ubiquity of Persons with Disabilities

In the disability community, despite advances in the legal recognition of disabled persons' rights, inadequate consideration and funding of their needs exacerbates an already impoverished climate of social inaction.[7] For example, government programs may focus on social housing for people with disabilities, but neglect to address the problem of stigmatization of the disability community.[8] Establishing the SDOH for "people with disabilities" is also highly complex because of varying categorizations of this population: a blind person's needs may be very different than a person who has lost a limb, or a person with depression, or type 1 diabetes. These

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differences also enter into ethical debates when it comes to triage policies, where people with disabilities are categorized according to an able-bodied definition of quality of life. In Ontario, for example, a draft COVID-19 triage protocol statement, the "Clinical Triage Protocol for Major Surge in COVID Pandemic", came under fire when the document was leaked to the public.[9] Over 200 disability organizations signed an open letter outlining concerns about its contents. The document was revised but has not been repealed despite a human rights challenge at the Ontario Human Rights Commission.[10,11] In Canada, people with disabilities also spoke out when the Canada Emergency Relief Benefit (CERB) for people out of work due to the pandemic, was determined to be almost twice what people with disabilities receive from the government and are expected to live on.[12]

Considering that the Centre for Disease Control (CDC) in the United States estimates that 26% of adults have some kind of disability, it is perhaps not surprising that people with disabilities have been adversely affected by the pandemic given the accessibility challenges facing this large group.[13] CDC data also shows that one in three adults with a disability does not have a regular health care provider, or has an unmet health care need because of the cost of care.[13] This systemic issue of access to health care has undoubtedly played into how people with disabilities have weathered the first six months of the coronavirus pandemic. While Canada has universal health coverage, its system nonetheless displays bias against disabled persons. Essential items, such as wheelchairs, crutches, ventilators, hearing aids, and medications are not covered by the federal program. Provinces have partial funding for these items, but these efforts remain largely focused on the indigent.

Moreover, during the first wave, public health data did not track the rates of infection among the disabled or chronically ill.[14] For example, the Ontario government released ongoing public health statistical updates which did not actively track disabled patients and did not include group homes where many disabled people reside because they are overseen by a different ministry. While experts identified the disabled as vulnerable to COVID-19, no effort was undertaken to assess the morbidity and mortality within this population and whether specific strategies might reduce infection rates. Disabled persons remained invisible within the early pandemic even as their personal support workers (PSWs) withdrew or fell ill. Access to food, household items and PPE became more difficult, and communication was impaired by the need to mask and/or by a lack of access to technology and the internet.

The problem of access to the physical environment is another systemic challenge not only for people with disabilities, but also for seniors or others with episodic mobility challenges. Despite awareness of universal design, building codes remain inconsiderate of people's fluctuating needs. Changes in housing construction would result in fewer admissions to long term care facilities – a tangible instance of how social policy influences the delivery of health care. One outcome of the global pandemic has been the realization that accommodations matter – overcrowded congregate settings kill. When the vast majority of citizens experienced working from home, the inadequacy of home offices, kitchen tables, and living room couches as working environments became evident. Not only people with disabilities, but everyone needs ergonomic home-and workspaces.

The renowned disabled academic Rosemarie Garland-Thomson writes: "No other social identity category is as porous and unstable. In fact, most of us will live on both sides of the volatile line between disabled and nondisabled".[15] We all experience morbidity at varying stages in our lives, some of our impairments may be temporary, some may be congenital, some may be permanent, and some may gradually emerge in the diminishment of old age. In sum, we all have a vested interest in getting things right for the disabled because ultimately, they are us and we are them.

Systemic Inadequacies of Care for the Elderly

The virus also lays bare the fact that the most vulnerable in our society, the elderly, are failed by "the system." Worldwide, whether the elderly reside in facilities or at home in multigenerational households, COVID-19 was far more lethal to them compared to the rest of the population. The Atlantic Monthly states that over 40% of American deaths have occurred in nursing homes.[16] Olga Khazan writes: "In just one New Jersey nursing home, at least 53 residents died after the sick were housed with the healthy and staffers had little more than rudimentary face shields for protection".[16] As of the end of the summer, California, New York, New Jersey, Massachusetts and Pennsylvania had the highest death rates in these facilities, exceeding 3,300 individually. Florida, Illinois, Texas, Maryland and Connecticut followed close behind.[17] In 15 states, over half the deaths had occurred in this population.[18] In Italy, the reported average age of deceased patients is 81.[19] As of the end of May, Swedish seniors, aged 70 and above, experienced over 50% of COVID-19 related deaths in that country.[20] In Canada, the provinces of Ontario and Quebec reported over 40% of COVID-19 cases in persons over 60. Nursing home residents accounted for over 80% of deaths in Canada during the first wave – one of the worst in the world.[1]

Many countries lack coordinated plans which integrate elder care with their broader health care systems. An Austrian report states that it had problems with PPE in its institutions because no one had thought to prepare the sector for the new coronavirus.[21] When the Canadian Armed forces were deployed to assist in the COVID-19 outbreaks in several long term care homes in Ontario and Quebec, they reported that "numerous forms of unhygienic and dangerous behaviour" were contributing to the spread of infection.[22] If public health and building codes required proper infection control and design, it would mean that vulnerable individuals would not have to share bedrooms and be exposed to infectious pathogens. While it is true that advanced age, chronic illness, and disability create a high degree of innate frailty, Canadians can no longer ignore that these individuals are also sick and dying because they live in over-crowded, under-funded environments.

This coronavirus health crisis in long term care in Canada is also causing a mental health crisis for seniors for have endured social isolation from family, friends, and each other for several months. Further lockdowns are likely when a second wave of the virus develops. Provincial governments initially approached the pandemic solely from a medical perspective, imposing aggressive restrictions to control viral spread. In the midst of a dire labour shortage, family members and PSWs were banned from entering senior homes. In some facilities, no extra personal items of any kind were allowed into the building including food items made or bought by families, flowers, or clothing, and all in-house social activities were stopped. In Ontario, long term care administrators were told that acute care

hospitals would not accept transfers from seniors' residences, even if patients were critically ill. These strategies, consequently put a massive strain on an already understaffed sector, resulting in more staff absences or turn around, and cognitive decline of seniors who lack social interaction and mental stimulation.[23] Lack of staff to care for residents resulted in many elderly dying from dehydration and even malnutrition in some cases.[24] Family advocates reacted strongly to these policies, and pressured provincial governments to come up with better alternatives to what many felt to be inhumane restrictions. Jianyang Fan, a regular contributor to The New Yorker recently published a piece about her anguished attempts to have her mother's PSWs reinstated at a nursing home where her mother lay completely immobile and ventilator-dependent with ALS. Those in charge of long term care seemed to respond rigidly to the threats of the first wave of COVID-19, failing to take into account the severe mental health toll on an already stressed and cognitively fragile population, nor modifying visitation rules as scientific knowledge and capacities evolved and as it became clear families and friends were prepared to undergo rigorous testing and isolation in order to care for loved ones.

The early stages of the pandemic exposed nursing homes' and other congregate settings' pervasively feeble architecture, inadequate funding and chronic labour incapacity. British Columbia's Senior's Advocate, Isobel Mackenzie, and the British Columbia government are conducting a survey of seniors in British Columbia to understand the deeper impact the pandemic has had on seniors and their families.[26] Another advocate in Alberta, Dr. Lorian Hardcastle, writes, "The only thing that could further exacerbate the devastation in the long-term care sector is if governments fail to seize this opportunity to make long-overdue changes".[27]

Low-income Essential Workers as the New Precariat

The high infection rates among low paid labourers such as cleaners, garbage collectors, grocery checkout workers, public transit workers, meat processing plant workers, and low-level health care workers are also explained by systemic inadequacies. Immigrants tend to occupy these roles in many industrialized countries. In Sweden, émigré Syrian and Iraqi communities experienced much higher rates of infection and mortality. In the UK and the US, people of colour (Hispanics, Blacks and South Asians) are dying in disproportionate numbers. They have a 70% greater chance of dying of the coronavirus than Whites.[28]

These alarming statistics demand social analysis and point to how systemic employment issues have exacerbated the spread of the virus. For example, many low-level workers continue to labour in high risk workplaces because their low wages and lack of benefits keep them too impoverished to search for alternatives. They often live in crowded circumstances and use public transport, raising their potential to catch and transmit the virus. In Alberta, the largest outbreak occurred in a meat-packing plant staffed by refugees and recent immigrants who butchered in an overcrowded premise. Multiple family members worked for the same employer and workers car-pooled and shared households in order to save money. In Ontario, migratory agricultural workers bore a heavy burden of disease as they were housed in run-down, congregate settings with little or no privacy and inadequate sanitation. Further, government mandating higher wages for caring and other forms of high risk unskilled labour would result in less exposure and risk to COVID-19 by being able to work in a single setting and being able to afford proper housing and transportation. One lesson that must be learned from this pandemic is that a safe workplace is an essential SDOH.

For the care they provide to the elderly and the disabled, PSWs – again often composed of overqualified immigrants and refugees – are undervalued, overworked labourers. As of November 1, 2020, staff composed 29% of long-term care COVID-19 cases in Ontario.[29] Negligible pay rates meant that many health care aides worked at multiple facilities to earn a living wage. This led to the spread of infection between multiple care sites. Moreover, in Ontario, infected PSWs were asked to work in care homes because extreme staff shortages meant that patients were dehydrated and lying in their own waste. Additionally, due to privatization of nursing homes, both Quebec and Ontario governments struggled to enforce administrative oversight of these facilities.

This class of worker in Western industrialized countries has been identified as the new "precariat" – or precarious proletariat – meaning a person working under uncertain and even dangerous conditions.[30] Given that those who care for the aged and disabled are at the bottom of the social and health-care hierarchy, little consideration is paid to this sector in good times, and almost no attention was paid to it in pandemic planning. This results in weak regulatory oversight, poor management, lack of staff training, and ongoing shortages of PPE, thereby contributing to increased infection rates in these vulnerable groups and facilitating viral spread to the larger community.

One unanticipated outcome of the COVID-19 pandemic has been the untold effects on a workforce suddenly forced to change business practices. For example, while employers have often rejected virtual work as an accommodation for its disabled employees, forcing people to take disability leave instead, it is now the primary form of labour during the pandemic. Just as families of disabled and chronically ill individuals who have been forced out of the workforce become more financially fragile and more likely to need state subsidy, the COVID-19 pandemic is laying waste to whole industries and fleets of laid-off workers are becoming more economically vulnerable. Workers who still have jobs may be wishing they and their employers had invested in accommodations earlier for working from home, never planning for a time when they too might be in a position of vulnerability and uncertainty.

Conclusion

By refusing to integrate marginal individuals, we needlessly fail them, and we fail ourselves. This social triage, where issues facing vulnerable populations have not been designated as a priority, has resulted in devastating pockets of COVID-19 outbreaks among disadvantaged segments of society. In hindsight, our response to the COVID-19 pandemic reveals systemic inadequacies that ignore the eventuality that we will all experience disease, disability, and vulnerability at some time in our lives. The pandemic shows how seemingly unrelated and distant policy decisions result in increased rates of infection and deaths in specific populations. Social conditions play an enormous role in pandemics. If we more consciously adjusted our attitudes, behaviours, environments, and policies to truly integrate our human vulnerabilities into all aspects of our lives we would have a far more resilient society, more capable

of responding to crises and emergencies and also likely to produce greater overall well-being. COVID-19 highlights our inherent frailties. Instead of ignoring them, we should embrace them, thereby making us a more capable and strong society.

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Declaration of Author's Competing Interests

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