Nothing about us without us:

Canadian vaccine decision making must involve disabled people

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Across Canada, national and provincial Covid-19 vaccine prioritization guidance and strategies have failed to appropriately include people with disabilities. Since the early goal of vaccination was to reduce severity, those at higher risk of severe disease if infected were meant to be prioritized early in vaccination campaigns, directly reducing their chance of death due to Covid-19. Older adults and some other higher-risk groups were therefore accorded high priority. However, younger disabled people were not prioritized for vaccines at levels commensurate with their risk of severe Covid-19 outcomes. Consequently, Canadian national policy recommendations have been incongruent with peer countries' vaccine prioritization, scientific evidence, and priorities expressed by Canadians regarding how we should allocate Covid-19 vaccines. To avoid repeating these mistakes, current and future pandemic planning must include disabled people as full members of decision-making committees, in keeping with the longstanding demand of disabled people: "Nothing about us without us." (1)

Ableism is "stereotyping, prejudice, discrimination, and social oppression toward people with disabilities," (2) and is a known and systemic problem in health care and in society more broadly. (3) Ableism has large negative impacts on health and well-being, as documented via seven waves of survey data collected from 2002 to 2014 across 32 European countries (total n=18,660) examining the effects of different sources of discrimination on overall health and well-being, controlling for life circumstances such as marital status, employment status, and income, and including factors such as racism and sexism. (4) No similar survey has assessed the experiences of disabled people in Canada, defined by Statistics Canada as those with physical, intellectual, sensory, or mental health conditions. This group comprises 22% of people in Canada aged 15 years and older. (5)

Covid-19 and associated public health policies have highlighted and compounded systemic ableism. (6) Many chronic and acute medical conditions are associated with elevated risk of hospitalization and death due to Covid-19; for example, solid organ transplant (7), advanced kidney disease (8), Down syndrome (9), other intellectual disabilities and mental health conditions. (10) Such conditions and others show substantially elevated risk of hospitalization and death due to Covid-19, even among younger age groups and after adjusting for other relevant factors.

Peer countries accordingly identified such conditions as high priority for the first two doses of Covid-19 vaccines. In the United Kingdom, people with such high-risk conditions were prioritized for vaccination alongside those aged 70 and older. A second group of conditions associated with somewhat lower but still substantially elevated risk of Covid-19 hospitalization and death, such as diabetes, leukemia, liver disease, lupus, and severe or profound learning disability, were assigned vaccination prioritization after those aged 65-69 and before people aged 60-64 without health conditions. The UK strategy also allowed health professionals to identify people at risk due to unique and complex health histories

beyond the more common conditions listed above. (11) Other peer countries; for example, the United States, issued similar lists of priority groups for individual states to consider in their plans, interleaving age ranges and categories of health conditions. (12) Prioritization not only addresses timing of access to vaccines by severity, but also directs how access is enabled. For example, when people receiving dialysis or home care are prioritized for vaccines, dialysis clinics and people's homes are spotlighted as possible vaccination sites. Relying on one-size-fits-most approaches for vaccine administration can further exacerbate inequities.

Unlike the peer countries above, Canada's national guidance did not prioritize people with health conditions at levels commensurate with risk of severe Covid-19 outcomes, even though 89% of Covid-19 deaths in Canada in 2020 occurred among people with one or more comorbidity. (13) When determining overall national guidance for Covid-19 vaccine prioritization, rather than adopting a scientific approach similar to those of peer countries, the National Advisory Committee on Immunization (NACI) review categorized odds ratios into four categories, then examined whether people with two or more conditions fell in a different category than people with no conditions. (14) Adjusted odds ratios, hazard ratios, and relative risks of severe Covid-19 outcomes associated with specific conditions range from under one to over ten. (9) Combining such disparate effects averages risk in a way that dilutes the very high risk borne by specific, small groups.

Based on this diluted-risk approach, NACI placed all people under the age of 60 with any high-risk health condition in Stage 3, last of the priority groups, together with people aged 50-59 and non-frontline health and essential workers. The recommendations advised that each stage be completed before proceeding to the next. Younger people with conditions putting them at substantially elevated risk of hospitalization and death were subsequently not prioritized for vaccination alongside older people at similar or lower risk. Figure 1 shows case fatality rates (death among those diagnosed with Covid-19) for different age groups in Canada prior to the availability of vaccines (15) alongside case fatality rates for selected conditions. As is evident in the Figure, people with high-risk conditions were not prioritized for vaccination at a level commensurate with their mortality risk. The lack of prioritization for vaccines is especially problematic given international and Canadian ethical guidance that disabled people may not be prioritized for treatment in the event of health care resources shortages. (16,17)

Figure 1 about here

In addition to lack of alignment with evidence and with peer countries' guidance, the failure to prioritize people with health conditions does not reflect Canadians' values. Consultations conducted by the Public Health Agency of Canada showed that expert stakeholders' top priority for vaccination was those at highest risk of death due to Covid-19. (18) Similarly, public polls showed that, "Canadians prioritize those with underlying medical conditions (57%) and the elderly (53%) for early immunization if supply of Covid-19 vaccine is limited." (19) Like NACI's initial misaligned prioritization recommendations, subsequent recommendations also failed to incorporate the realities of those with comorbidities. For example, the rationale for recommending that no one under the age of 55 receive an Oxford/AstraZeneca vaccine was based on risk-benefit calculations for younger people as a whole, ignoring the additional risk borne by those younger than 55 with comorbidities. (20)

Failing to consider the modifying effects of health conditions and disabilities in a pandemic response disproportionately impacts racialized communities and people living with fewer financial resources. Stemming largely or in part from structural racism, there is a higher prevalence of chronic medical

conditions associated with greater Covid-19 severity in some racialized communities, who face barriers to accessing health care and chronic disease primary prevention resources. (21) Disabled people in Canada experience poverty at disproportionately high rates (22) and are therefore more likely to live in crowded settings with older ventilation systems, putting them at higher risk of Covid-19 infection. Eighty-five percent of people experiencing homelessness in Canada have at least one chronic illness. (23) Analyses of case-fatality in Ontario showed that health conditions were independently associated with case-fatality, even after adjusting for neighbourhood-level factors like income. (24) Similarly, analyses in the US using randomized venue-based sampling showed that Covid-19 exposure did not vary among people in different racial and ethnic groups, suggesting that disparities in Covid-19 outcomes may not be due to differences in exposure and instead may be associated with prevalence of underlying conditions and disparities in access to care. (25) Taken together, such analyses suggest that patterns in negative Covid-19 outcomes associated with neighbourhood or ethnicity likely reflect disparities in prior health status, a noted effect of structural racism. (26) In other words, by failing to appropriately prioritize people with health conditions for vaccines, Canadian policies have demonstrated not only systemic ableism, but also systemic racism.

The United Kingdom was able to develop precise risk estimates incorporating disabilities and health conditions to determine vaccine prioritization because they have national datasets we lack in Canada. (27) However, if the problem in Canada were simply imprecision due to lack of data, we would expect to see disabled people prioritized sometimes too low, sometimes too high. Instead, we observe prioritization consistently too low, indicating that the problem is neither a lack of data nor a lack of scientific expertise, but rather, a lack of care for disabled people. Such lack of care occurs when committees function within ableist systems and when disabled people are not involved in decision making.

Given the disproportionately low representation of disabled people in health care (28) and science (29) it is not surprising that committees composed of people in health care and health research might fail to adequately consider the needs of those with disabilities. It is unfortunately common for non-disabled people to implicitly and explicitly undervalue the lives of disabled people. (30,31) Public health has a long history of ignoring ableism as a source of health disparities (32) and public health literature scarcely focuses on disabled people's immunization-related needs, with a particularly notable lack of studies of disabled adults. (33)

There will be more decisions to make in this pandemic and in future similar situations about who gets priority for vaccination and other services, and why. At a minimum, committees making prioritization recommendations or decisions must include disabled people as full members to ethically and responsibly represent the interests of disabled people across Canada. It matters who is at the table.

Figure 1. Covid-19 case fatality rates (prior to vaccine availability) and stage of vaccine priority assigned by NACI

(a) Age 80 and older: 25.9%; Age 70-79: 11.3%; Age 60-69: 2.8%; Age 50-59: 0.6% (15)
(b) Solid organ transplant (hospitalized patients): 23.2% (7)
(c) Chronic obstructive pulmonary disease: 20.1%; Advanced kidney disease: 19.5%; Cancer: 10.8%; Immunocompromised: 10.3%; Diabetes: 9.6%; Advanced liver disease: 9.5% (24)
(d) Intellectual disability: 8.2% (34)

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