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# 'It's life and death': As Ontario hospitals face new wave of COVID-19, disability advocates want triage protocol released

Brendan Kennedy

Opposition critics and disability advocates are calling on Ontario's government to publicly release its COVID-19 triage protocol, which would guide doctors on how to determine who should get life-saving treatment if hospitals are overwhelmed by coronavirus patients.

The purpose of the protocol, which would only be invoked as a last resort if critical care resources needed to be rationed, is to minimize overall mortality by prioritizing patients with the best chance of survival.

The Ministry of Health says the protocol is still being reviewed and will not be made public at this time.

A draft version of the protocol, which was first leaked in March, was criticized for discriminating against people with disabilities. A revised draft was circulated this summer as the province solicited feedback from certain groups, including some disability advocates, who said the revised draft was still discriminatory.

Among their main concerns was the inclusion in the protocol of the Clinical Frailty Scale, a nine-point grading tool originally designed to assess the relative frailty of elderly patients.

Patients who are "very fit" score a one on the scale, while terminally ill patients with fewer than six months to live score a nine. A patient scores higher on the scale the more dependent they are on others for basic activities based on their condition two to four weeks before admission to hospital.

Disability advocates said the scale would not take into account whether someone could achieve certain tasks with accommodations.

"That's extremely problematic," said Mariam Shanouda, a lawyer for the ARCH Disability Law Centre. "We are in effect saying that a prerequisite for critical care is not having a disability at all."

Although it is just one of 13 ineligibility criteria included in the draft protocol, scoring higher on the Clinical Frailty Scale could lead to a patient being excluded from treatment in the event that the number of critical care patients exceeds a hospital's capacity.

Critics say a triage protocol that would be invoked if hospitals are overwhelmed by patients discriminates against people with disabilities.
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The protocol states that the tool would only be used to estimate chances of survival for patients with "progressive illness and generalized deterioration in health status" and not for nonprogressive conditions. But Shanouda and other advocates say the scale is inherently discriminatory against people with disabilities, no matter how it is used.

Shanouda also pointed to the fact that the scale was not designed for this purpose. Guidelines for using the Clinical Frailty Scale — published by its inventor, Dr. Kenneth Rockwood — state that it has not been validated for people under 65 years old or for people with "stable" disabilities. The government's draft protocol anticipates using it for all

adults.

On Friday afternoon, a spokesperson for the Ministry of Health said via email that the ministry is currently reviewing the latest proposal from its Bioethics Table, the government-appointed group of physicians and bioethicists enlisted to develop the triage protocol. Since the proposal is under review, the ministry is "unable" to share it publicly, she said.

The spokesperson said the ministry heard the concerns from disability rights experts regarding the Clinical Frailty Scale, but could not say whether or not it is included in the latest proposal. The new proposal includes "significant revisions, including revisions related to human rights and equity," she said, adding that it is the result of "extensive consultation over the summer including with the Ontario Human Rights Commission as well Indigenous health leaders, disability rights experts and stakeholders representing marginalized populations and others who may be disproportionately affected by critical care triage."

David Lepofsky, chair of the Accessibility for Ontarians with Disabilities Act Alliance, said the government's lack of transparency is a major concern.

"This is an issue for which there should be a lot of sunshine, not secrecy," he said. "It's life and death."

Lepofsky, who obtained a copy of the draft protocol during this summer's consultations, published it on his group's website. The province itself has not released any of the drafts or the Bioethics Table's recommendations.

With the province now engulfed in COVID-19's second wave and hospitals raising concerns about their capacity to handle a surge in patients, there is increasing pressure to make the triage protocol public.

On Wednesday, Ottawa MPP Joel Harden, the NDP's critic for people with disabilities, submitted written questions in the legislature asking Health Minister Christine Elliott to make public the triage protocol.

"We needed this information months ago, but at this point it's unacceptable that people with disabilities don't know the answer to these questions," Harden said in an interview. "In the event that people who are similarly affected by this virus are waiting for life-saving equipment, we certainly don't want any assumptions made about someone's quality of life as a person with a disability and therefore whether or not they should access a ventilator any sooner than anybody else."

Critics of the draft protocol also say it lacks due process by not including an appeal mechanism for patients and their families.

"There is nothing in their protocol, including the revised protocol, to ensure fairness and due process," Lepofsky said. "I'm not saying (an appeal) could go on for weeks and weeks, but we put forward in our submissions a proposal for a rapid, informal — but necessary — set of due process protections."

Roxanne Mykitiuk, a professor at York University's Osgoode Hall Law School and an expert in disability law and bioethics, said the triage protocol should limit its scope to assessing a patient's ability to survive COVID-19 and not try to estimate their lifespan beyond that.

"You can't really make that determination accurately, so let's not try," she said. "Let's just make the assessment on a short-term basis."

Mykitiuk, who was invited by the Bioethics Table to give feedback on the draft protocol and worked with the ARCH Disability Law Centre on their submissions, said the protocol should explicitly state that any triage decision must avoid discrimination and must adhere to human rights standards. "They need to expressly say that the presence of disability is not a permissible basis for giving lower priority for intensive care."

**CLINICAL FRAILTY SCALE**

1. Very fit — Robust, active, energetic and motivated. Regular exercise.

2. Well — No active disease symptoms, but less fit than first category.

3. Managing well — Medical problems are controlled, but not regularly active beyond walking.

4. Vulnerable — Not dependent on others for daily help, but symptoms limit activities.

5. Mildly frail — Need help in "high order" instrumental activities of daily living (IADL), such as finances, transportation and heavy housework.

6. Moderately frail — Need help with all outside activities and keeping house, often need help with stairs, bathing.

7. Severely frail — Completely dependent for personal care, but stable and not at high risk of dying.

8. Very severely frail — Completely dependent, approaching the end of life. Typically would not recover from even

a minor illness.

9. Terminally ill — Approaching end of life, with a life expectancy of less than six months.

*SOURCE: Geriatric Medicine Research, Dalhousie University*

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