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Part of the 'Surplus Population"?: Disability Ethics in the Midst of a Pandemic

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“Surplus Population”??!!

- Charles Dickens’ classic Christmas tale, *A Christmas Carol*, features the following exchange between curmudgeon, Ebenezer Scrooge, and charity canvassers:

“Surplus population”???

Time of Crisis = Difficult Conversations and Fraught Ethics

- In times of crisis, such as the current pandemic, clinicians are compelled to have difficult conversations, and make difficult decisions, about which patients will get access to potentially life-saving treatment, and which ones won't.

Time of Crisis = Difficult Conversations and Fraught Ethics

- It is within the context of such decision-making, which is already intensely ethically fraught, that latent ableist notions and thought processes, which are chronic within health care and health ethics, become extremely problematic, and even lethal.

Objectives for this Presentation

- Identify and explore understandings of disability that were prevalent in Canadian society in general, and Canadian healthcare in particular, prior to the advent of the COVID-19 pandemic.
- Outline the foundational concepts and principles of a Disability Ethics lens for evaluating healthcare policies and interventions.
- Examine the ways in which a Disability Ethics lens is articulated in the recommendations that Canadian disability rights organizations have issued regarding COVID-19 critical care triage protocols.

Objectives for this Presentation

- Explore the extent to which various provincial Critical Care Triage Protocols either contravene or align with the recommendations of disability rights organizations.
- Discuss the implications that clinical compliance or non-compliance with disability-ethics-based recommendations regarding COVID-19 critical care triage protocols will have in terms of either improving disabled people's access to medical care, both during and after the pandemic, or, further entrenching potentially-lethal ableism in Canada's healthcare system.

Societal and Medical Ableism: Pre-Existing Conditions in the Context of a Pandemic

- **Ableism is discrimination** on the basis of physical, mental, intellectual or sensory disability
- Disability is equated with weakness, incapacity, cure or elimination
- The concept is deeply-ingrained in society
- Traditional approaches to disability are often medicalized
- Healthcare providers are not exempt from these perceptions and this impacts treatment options

Foundational Concepts and Principles of a Disability Ethics Lens for Evaluating Healthcare Policies and Interventions

- The guiding principle of disability ethics is “Nothing about us without us.”
- There can be no truly ethical discussions or debates about biomedical issues involving disability that do not include, and indeed, centre around, the perspectives of disabled people.

Foundational Concepts and Principles of a Disability Ethics Lens for Evaluating Healthcare Policies and Interventions

- Inherent opposition between the conventional biomedical understanding of disability as an intrinsic deficit and the disability ethics conceptualization of disability as a naturally occurring human variation, and, therefore, a neutral characteristic which has the potential to become a positive marker of identity.

Foundational Concepts and Principles of a Disability Ethics Lens for Evaluating Healthcare Policies and Interventions

- Fundamental differences in the ontological meaning of disability within conventional health ethics versus disability ethics result in equally fundamental differences in the ethical principles and values that are predominantly associated with the phenomenon of disability in each of the two perspectives.

Autonomy – in Health Ethics

- **Autonomy** is generally considered to be the cardinal principle of contemporary health ethics.
- Commonly defined as an individual's capacity for self-determination or self-governance.
- This definition infers a necessary connection between having a claim to autonomy and having the capacity to make rational decisions in accordance with one's authentic, articulatable desires.

Autonomy – in Disability Ethics

- Disability ethics acknowledges the importance of autonomy while, at the same time, recognizing the fact that all human beings are ultimately interdependent on one another.
- Disability ethics thus seeks to balance the importance of autonomy with the necessity of protecting the most vulnerable in our society, thereby preserving the **common good**.

The Common Good

- Ethicist John Rawls defined **the common good** as "certain general conditions that are... equally to everyone's advantage."

The Common Good

- ❑ Ironically, in the decades leading up to this current pandemic, the notion of **the common good** as a viable ethical principle had, for all intents and purposes, become obsolete due to the rise of **autonomy** as the cardinal ethical principle in Western societies.
- ❑ Curiously, and, we would argue, serendipitously for humanity, the COVID-19 pandemic has initiated the comeback of the common good as the linchpin for soliciting compliance with the public health policy of social isolation.

Vulnerability

- Within traditional bioethics, vulnerability is commonly defined as being at increased risk of harm, and/or having a decreased capacity to protect oneself from harm. Vulnerability is thus ubiquitously conceptualized as the ultimate threat to autonomy.

Vulnerability

- A disability ethics perspective views vulnerability as an inevitable, universal consequence for disabled people living in an ableist society in which there is a commonly held assumption that a disabled life is ubiquitously, even invariably, blighted and aberrant.

Quality of Life

- In bioethics, quality of life is a term used to refer to a person's emotional, social and physical wellbeing, their intellectual capability, and their ability to perform the ordinary tasks of living within a community.

Quality of Life

- In disability ethics, quality of life tends to be viewed as a concept which must be disentangled from ableist notions of normativity before it can be rehabilitated into usefulness. When this disentanglement proves impossible, the concept of **human flourishing** offers a viable alternative for describing and quantifying a person's enjoyment of life, with, not in spite of, disability.

Articulation of a Disability Ethics Lens in the Recommendations that Disability Rights Organizations have issued regarding COVID-19 Critical Care Triage Protocols

- ❑ Disabled people often face disproportionate risk of acquiring COVID 19
- ❑ Outdated understandings of disability should not influence health care provision
- ❑ Stigmatized assumptions about quality of life should not influence access to care

Potential Impacts of COVID-19 Critical Care Triage Protocols on the Future Treatment of People with Disabilities in Canada's Healthcare System

□ Where does all this leave us?

Things I've been hearing from people in healthcare:
“Triage protocols would only come into effect in Canada if and when a province's healthcare system is overwhelmed, to the point where rationing of equipment becomes necessary. No current projections show that situation happening in Canada. Therefore, it's not a cause for concern.”

Potential Impacts of COVID-19 Critical Care Triage Protocols on the Future Treatment of People with Disabilities in Canada's Healthcare System

□ OR...

- “If you're ill enough to require a ventilator, and you have a pre-existing condition or disability which compromises your lungs, your chances for survival are minimal, with or without a ventilator. So, again, all the angst over triage protocols is, essentially, groundless.”

My FIRST Response



My 2nd Response: “I come in peace...”

- “Hey, I work in an ethics centre, with physicians, nurses, philosophers, etc. I know that the vast majority of clinicians and ethicists ... **are not** eugenicists or fanatical utilitarians, out to reduce the surplus population of disabled people.”

“However...”: The Enduring Dangers of Medical Ableism

- Much as it is with COVID-19, most people infected with medical ableism exhibit only mild symptoms, but can, nonetheless, spread the infection to others, with, potentially, deadly results.

“However...”: The Enduring Dangers of Medical Ableism

- But, unlike the danger of COVID-19, the dangers posed by medical ableism will endure long after the current pandemic has ended. People with disabilities will surely find it even more difficult to entrust themselves to a medical system that has openly deemed their lives to be of lower priority to be saved in a time of crisis.

Our Recommended Treatment for Medical Ableism

- It behoves healthcare practitioners and clinical ethicists to make space at the protocol-drafting table for disability scholars and advocates.

Our Recommended Treatment for Medical Ableism

- Granted, most disability scholars and advocates will not have the same kind of biomedical knowledge that clinicians have.
- Conversely, however, they bring to the table an in-depth knowledge of the ways in which disabling conditions actually impact human life, a knowledge to which most clinicians and ethicists do not have access.

Our Recommended Treatment for Medical Ableism

- Therefore, nothing short of a balance between clinical and experiential knowledge of disability around tables where both critical care protocols and healthcare curricula are created will be effective in reducing the harms people with disabilities face because of medical ableism, during this COVID-19 pandemic, and beyond.

Thank you!!!!

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