


COVID-19 pandemic, the scarcity of medical resources, community-centred medicine and discrimination against persons with disabilities

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ABSTRACT

This research aims to examine access to medical treatment during the COVID-19 pandemic for people living with disabilities. During the COVID-19 pandemic, the practical and ethical problems of allocating limited medical resources such as intensive care unit beds and ventilators became critical. Although different countries have proposed different guidelines to manage this emergency, these proposed criteria do not sufficiently consider people living with disabilities. People living with disabilities are therefore at a higher risk of exclusion from medical treatments as physicians tend to assume they have poor quality of life, whereas access to medical treatment should be based on several parameters, including clinical data and prognosis. However, the COVID-19 pandemic shifts the medical paradigm from person-centred medicine to community-centred medicine, challenging the main ethical theories. We reviewed the main guidelines and recommendations for resources allocation and examined their position toward persons with disabilities. Based on our findings, we propose criteria for not discriminating against people with disabilities in allocating resources. The shift from person-centred to community-centred medicine offers opportunities but also risks sacrificing the most vulnerable people. The principle of reasonable accommodation must always be considered to guarantee the rights of persons with disabilities.

BACKGROUND

Persons affected by any form of disability represent just under a fifth of the world population, and recent surveys report trends of further increase due to ageing and associated chronic health conditions.¹

During the current COVID-19 pandemic, people living with disabilities have several disadvantages that increase their vulnerability, as summarised in tables 1 and 2.

Additionally, during a crisis, the most concerning public health issue is the allocation of scarce resources such as ventilators and intensive care unit (ICU) beds. Several countries developed specific guidelines to manage access to medical resources, based on age and comorbidities, often denying such resources to older people and people with severe and complex disabilities. Various organisations working for the rights of people living with disabilities^{2–5} have accused medical institutions of ableism (discrimination and social prejudice against people living with disabilities) in triage.⁶

Our paper aims to highlight which ethical principles underlie these protocols for the triage of scarce medical resources and, in particular, the extent to which the application of these principles involves a shift in the medical paradigm from person-centred to community-centred medicine.

We believe that this shift would not be consistent with the UN Convention on the Rights of Persons with Disabilities (CRPD),⁶ to which any guideline on allocation of health resources must refer.

ABLEISM, ACCESS TO HEALTH SERVICES AND THE FUTILITY OF TREATMENTS

The CRPD reaffirms that all persons with disabilities must enjoy all human rights, including non-discrimination, equality of opportunity and accessibility in healthcare provision. Article 25 of the convention explicitly states that ‘discriminatory denial of health care or health services ... on the basis of disability’ must be prevented.

‘Reasonable accommodation’ is one of the main requirements stipulated by the CRPD. It is defined in Article 2 as the ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’.⁷ Failure to apply reasonable accommodation implies that it is impossible for people with disabilities to benefit from their rights. However, ableism is a well-known problem in healthcare accessibility.

Ableism refers to the assumption that each individual must meet the arbitrary standards set by the dominant group within society and consequently that persons with disabilities are inferior to able-bodied people or at least have to be postponed in the provision of limited resources or services.⁸ Ableism still represents an underestimated concept by many healthcare workers and policy makers in evaluating the equity of service provision to patients with disabilities and continues to limit healthcare accessibility. For example, the data in the literature have demonstrated both premature and avoidable mortality of people with autism and learning disabilities.⁹ In Italy, the ‘Charter of Rights for People Living with Disabilities in Hospital’ indicates the presence of ‘health barriers’¹⁰: architectural, organisational and cultural barriers that prevent or limit access to health services of people living with disabilities, hindering their right to health.¹¹

Table 1 Vulnerability factors to COVID-19 in persons with disabilities

Area of vulnerability	Factor
Prevention and management of infection with SARS-CoV-2	<ul style="list-style-type: none"> ▶ Use issues and low compliance with personal protective equipment (ie, safety helmets, gloves, eye protection, high-visibility clothing, safety footwear and safety harnesses). ▶ Low levels of health literacy (for persons with cognitive and developmental disabilities). ▶ Low compliance with complex hygiene rules (for persons with cognitive and developmental disabilities). ▶ Reliance on other people for care. ▶ Living in congregated settings. ▶ Small social networks. ▶ Residential instability and homelessness.
Other physical health issues	<ul style="list-style-type: none"> ▶ Pre-existing medical conditions, including multimorbidity. ▶ Specific immunological assets. ▶ Lack of accessibility to healthcare services and unmet needs for healthcare. ▶ Low standard of living.
Mental health	<ul style="list-style-type: none"> ▶ Prepandemic lack of accessibility to mental health services and unmet mental health needs. ▶ Pre-existing low standard of living. ▶ Pre-existing psychological vulnerability (especially in persons with intellectual disability, autism and other developmental vulnerabilities).

The main principle of ethical and legal justification of the medical act is that its expected benefits should be superior, or at least equal, to the foreseen risks. Physicians must assess the proportionality of treatment and avoid therapeutic and diagnostic obstinacy or the futility of treatment.

Especially when applied to people with severe disabilities, the proportionality and futility of medical treatment are highly debated concepts.

The US National Council of Disability highlights that decisions on the futility of care are affected by the prejudice linked to the quality of life of people living with disabilities, which is considered very poor. However, quality of life must not be

evaluated on a functional basis but on a person's satisfaction with their life.¹²

Deceased-donor organ donation is the ultimate example of the allocation of poor resources. Even in this context, people with intellectual disabilities are discriminated against, as pointed out by the US National Council of Disability report.¹³

The decision to exclude or include people with disabilities on the waiting list for transplantation must be based only on clinical data. In patients with learning or cognitive disabilities, health-related quality of life or IQ should not be a parameter to judge eligibility for transplantation.^{14 15}

COVID-19: the scarcity of medical resources and the shift of the medical paradigm

The COVID-19 pandemic led to a shift in the medical paradigm from person-centred medicine to community-centred medicine. This shift gives 'priority to community health above that of the individual patient in allocating scarce resources'.¹⁶ Accordingly, during this epidemic, the patient-physician relationship has also undergone a sudden and profound change and has moved away from the shared decision-making model.¹⁷

Medicine should be developed and affirmed by combining strategies and clinical options with the person's needs and values (person-centred medicine).¹⁸ In patient-centred medicine, the care should be 'respectful of and responsive to individual patient preferences, needs, and values' and should ensure 'that patient values guide all clinical decisions'.¹⁹ Care should include dignity, compassion and respect, always considering clinical, social, emotional and practical needs.^{20 21}

For people with severe cognitive disabilities, in which decision-making abilities are partially or completely absent, supported decision making has been developed. This is an individualised decision-making process that aims to make people living with disabilities the protagonists of their choices.²²

During a public health crisis, the community's health takes precedence over the individual's health. According to Berlinger,²³ a tension between equality and equity is created from an ethical point of view: 'expressed through the fair allocation of limited resources and a focus on public safety, and the patient-centered orientation of clinical ethics, expressed through respect for the rights and preferences of individual patients'.

During this pandemic, these models of relationships seem to have been put aside for a return to paternalism. Often under the guise of public health concerns and limited resources available,

Table 2 Distressing factors and other main factors with negative impact on the lives of people with disabilities

Area of impact	Factor
Social relationships and community participation	<ul style="list-style-type: none"> ▶ Social distancing. ▶ Closure of places and community activities. ▶ Interruption of the possibility to interact with significant caregivers.
Communication	<ul style="list-style-type: none"> ▶ Social distancing. <ul style="list-style-type: none"> – Use of face mask. ▶ Lack of accessibility to information and communication technologies.
Adaptive skills	<ul style="list-style-type: none"> ▶ Environmental and social changes. ▶ Drastic restriction or interruption of habitual activities. ▶ Support restriction. ▶ Restriction or discontinuation of rehabilitation and educational services.
Physical health	<ul style="list-style-type: none"> ▶ Restriction of healthcare services and exacerbation of accessibility issues. ▶ Altered biorhythms, including sleep-wake rhythm (especially during full lockdown). ▶ Reduction of sport and physical activity. ▶ Increase or decrease of food intake.
Mental health	<ul style="list-style-type: none"> ▶ Environmental and social changes (especially in persons with a strong need of routine/sameness, such as those with autism). ▶ Restriction of mental health services and exacerbation of accessibility issues. ▶ Exposure to adjunctive prejudice and discrimination, including the belief on impossibility to comply with the pandemic or make one's own decisions. ▶ Altered biorhythms, including sleep-wake rhythm (especially during full lockdown).

the physician has abandoned the shared decision-making model. Instead, the crisis standard of care (CSC) is embraced, which is an optimal level of care that could be delivered during a catastrophic event; however, it requires substantial changes in the usual healthcare operations. The principles proposed by the CSC are fairness, duty of care, duty to steward resources, transparency, consistency, proportionality and accountability.²⁴ The CSC describes a framework that should be applied to prioritise the treatment of patients with the aim of maximising benefits. In clinical practice, during triage, it is only physicians who decide through criteria that may be subject to criticism. In several US states, the CSC has been challenged by advocates for people with disabilities because they encapsulate discriminatory guidelines. In addition, it is difficult in clinical practice to merge the triage process with a shared decision-making model. For these reasons, a triage committee should be established.

However, the fact that such a committee could profoundly influence the physician–patient relationship remains a concern, not to mention the ‘medical paternalism’ it might cause. Therefore, it would be appropriate for this committee to have as its members people living with disabilities or their advocates, so that the principle of ‘nothing about us without us’ can be ensured.

The main ethical theories are now faced with this shift of perspective. In particular, principlism from a perspective of community-centred medicine had to shape the principle of autonomy into that of solidarity; this is in contrast to utilitarianism, one of the most commonly employed ethical approaches in Anglo-Saxon cultures.

Savulescu *et al*²⁵ argued in favour of the utilitarian approach in the current pandemic. The fundamental principle to pursue is well-being, and freedom and rights are important only insofar as they ensure well-being. The aim is to achieve greater overall well-being, understood in terms of years of life and quality of life, not to save more lives.²⁶

From this approach, Emanuel *et al*²⁷ identified four fundamental values that can be interpreted in more than one way, and sometimes, they can even be:

- ▶ ‘*Maximise the benefits from limited resources*’. This can be interpreted as saving as many patients as possible or maximally increasing life expectancy by prioritising patients who are more likely to survive.
- ▶ ‘*Treat every patient equally*’. Equality can be applied by either casually selecting patients or distributing resources on a ‘first come, first served’ basis.
- ▶ ‘*Promote and reward the value of work*’. This provides people who can save lives or people that have saved lives priority access to limited medical resources.
- ▶ ‘*Give priority to those who are in critical conditions*’. This encourages the prioritisation of critically ill patients. These patients could either be the most clinically ill or the youngest whose life expectancy could drastically decrease if not properly treated.

Prioritarianism is another interesting perspective, which combines the criterion of general well-being by giving greater weight to worse-off individuals. Nielsen²⁸ argued that, also in pandemic crisis, severity of illness and age should not over-ride the social disadvantage, and this should remain a primary concern. Health policies should be put in place to relieve the effects of inequality amplified by the pandemic.

However, all of these recommendations do not specifically address the issues related to disability.

COVID-19: the scarcity of medical resources and people living with disabilities

Several institutions have proposed guidelines and recommendations about the rightful allocation and management of scarce resources. The Code of Medical Ethics of the American Medical Association (AMA) defines specific criteria to assess patients’ priority access to scarce medical resources as follows:

- ▶ Medical need (urgency of need).
- ▶ Likelihood of benefits.
- ▶ Change in the quality of life.
- ▶ Patients whose access to treatment might be fundamental to avoid premature death or extremely poor outcomes.
- ▶ The use of an objective, flexible and transparent mechanism to determine the patients that will receive access to medical resources or treatment when there are no substantial differences among patients.

The AMA Code also states that ‘it is not appropriate to base allocation policies on social worth, perceived obstacles to treatment, patient contribution to illness, past use of resources, or other non-medical characteristics’.

The British Medical Association ethical guidelines present critical issues regarding the applicability of reasonable adjustment.²⁹ To evaluate the benefits of intensive treatments, on its website, the National Institute for Health and Care Excellence has proposed the use of the clinical frailty scale. However, this scale cannot be applied to people with long-term disabilities.

The Italian Society of Anesthesia Analgesia and Resuscitation proposed general criteria to maximise the benefits for as many people as possible and consume the least resources possible to expand the number of beneficiaries. Age, probability of survival, life expectancy, the presence of comorbidities and functional status³⁰ are some of these exclusion criteria. The document highlights that denying access to intensive care by basing the decision solely on the criteria of distributive justice finds justification in the extraordinary nature of the situation.

The French Society of Anesthesia & Intensive Care Medicine states that in crises, it is not justifiable to renounce the principles of autonomy, benevolence, non-maleficence, solidarity and equity as distributive justice. Maximising the benefit and considering the indirect benefit are other principles that should be respected. The resources must be allocated without discrimination of age, religion, sex, presence of a disability, or social and economic position. However, age and presence of a disability should be considered when assessing the prognosis.³¹

It was also proposed to assign a score to all patients with an indication of requiring ICU hospitalisation, without exclusions a priori, based on: (1) the probability of surviving the hospitalisation by objectively assessing the severity of the acute disease; (2) the probability of long-term survival determined by the presence of comorbidities that decrease life expectancy; and (3) and priority for those who carry out works of public utility.³²

Allocation criteria for people living with disabilities: a proposal

Even when not explicitly stated, most of the previously cited criteria do not seem to root for the allocation of scarce resources to people living with disabilities. Kittay³³ argued how maximising benefits creates overt discrimination towards people living with disabilities. According to Kittay, ‘the benefits are unlikely to benefit disabled people, and surely not people with intellectual disabilities.... Benefits attach to people. So, who is benefited, and who decides what a benefit is or when it is maximized?’ Prejudices and public perception of people with disabilities and

their quality of life can be easily and unfortunately included in the protocols for the rationing of health resources.

Some organisations have claimed the right of people living with disabilities to undergo medical treatment, regardless of the benefit that the treatment will bring. This claim goes against the principles of medical ethics and risks turning into unnecessary suffering and pain for the patient who could be forced to undergo futile treatments.^{34 35}

None of the guidelines and recommendations examined recommend the use of Quality Adjusted Life Years (QALYs) to prioritise resource allocation. QALY is a controversial methodology for cost effectiveness analysis. It was accused of discriminating against people with disabilities and of considering their life of lesser worth.^{36–39} Two documents, one of National Council of disability, other of Partnership to Improve Patient Care organisation, argued against using the QALY^{40 41}

‘Primum non-nocere’ (non-maleficence) is one of the foundational ethical principles in medicine, and only therapies that are of real benefit to the patient should be proposed. In this context of resource scarcity, the challenge is to blend patient-centred medicine and community-centred medicine. Only in this way can the most vulnerable people be protected, including people living with disabilities. Even for the allocation of scarce resources in triage, people living with disabilities should be treated based on the equality of opportunities and non-discrimination, in accordance with the United Nations Charter of the Rights of Persons with Disabilities. Reasonable accommodation must also be applied in triage and care.

To this purpose, the National Health Service in the UK has developed clinical guidelines to support the management of patients with a learning disability and autism during the COVID-19 pandemic.⁴²

On behalf of The Italian scientific committee of the Charter of Rights of People Living with Disabilities in Hospital and the Italian Disabled Advanced Medical Assistance Centres,⁴³ the authors suggest the following criteria for allocating scarce resources to people living with disabilities:

- ▶ The principles of non-discrimination, equality, equality of opportunity, reasonable accommodation and the right to health under the CRPD must always be considered and applied.
- ▶ For people living with disabilities, the risk of death from respiratory failure is greater compared with the general population.^{44–46}
- ▶ It is necessary to consider the impact of intensive care treatments on near-term survivability and overall prognosis for that specific patient with a disability.⁴⁷
- ▶ Long-term survival is not an acceptable parameter to determine whether to withhold or withdraw life support treatments.⁴⁸
- ▶ Intellectual disability alone should not be accepted as an exclusion criterion.
- ▶ The expected quality of life of people living with disabilities and QALY should not be relied on.
- ▶ Usefulness to society cannot be accepted as the only criterion.
- ▶ People living with disabilities, even those with intellectual disabilities, should be involved in the decision-making processes according to their understanding and decision-making skills; this satisfies the legitimate request ‘Nothing about us without us’.
- ▶ Allow visits to caregivers of hospitalised people living with disabilities. Many hospitals have very restrictive policies. The caregiver is an indispensable tool to understand the needs (eg, pain) and wishes of the patient better in the context of shared decision making or supported decision making.

- ▶ If there are the conditions to undertake or suspend a specific treatment, palliative care must be guaranteed.
- ▶ Advanced care planning is a useful tool to identify the best therapeutic strategy and decision for every patient.

These associations are promoting actions for these criteria’s dissemination and acceptance both from a cultural and regulatory point of view.

CONCLUSIONS

Persons with disabilities do not have special rights but do need special tools that guarantee the rights they share with every other people. The CRPD states these universal rights and prescribes various tools for assuring them: principles of non-discrimination, equality, equality of opportunity, the right to health and reasonable accommodation. However, we found that the ethics underlying most recommendations and guidelines for allocating scarce health resources may be based on principles that discriminate against persons with disabilities.

While it is not easy, it is necessary to try to save the specificity of medical care for each patient and the value of each human life even in the current pandemic. We also believe that during a crisis and when dealing with scarcity of resources, the proportionality of treatment should guide decision making.^{49 50} The ‘principle of therapeutic proportionality’ affirms the moral obligation to provide patients with treatments that preserve a relationship of due proportion between the means employed and the end sought. The benefits and risks associated with the treatment, the expected outcomes, the burdens in terms of quality of life and the physical and moral strength of the individual patient must be considered for this assessment. The authors believe that for an individual patient, in a certain context, the benefits should outweigh the burdens in terms of risks and complications of treatment, quality of life, and physical and moral strength.

The shift from person-centred to community-centred medicine offers both risks and opportunities: the interests of the individual are sacrificed for the safety and health of the community, and this may especially affect the most vulnerable people. However, privileging the health of an entire community can also be a tool to protect the most vulnerable ones included within the community, but this can only happen if the community treats these people as full members. Recommendations and guidelines for the allocation of scarce health resources need to consider the rights of the most vulnerable, including people with disabilities; in particular, they must always apply the principle of reasonable accommodation.

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