

# IS THE USE OF DALYS AND QALYS ETHICALLY PERMISSIBLE IN TRIAGE DECISIONS? COVID-19 AND EQUITY CONSIDERATIONS FROM A QUEER-CRIP PERSPECTIVE

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## ABSTRACT

This paper explores the symbolic and material implications of the use of DALYs and QALYs as priority or tie-breaker criteria in triage decisions. It aims to answer the question of their ethical permissibility based on the case of the COVID-19 pandemic. For this purpose, theories framed in a queer-crip perspective and ethical frameworks of equity will be used. From a queer-crip perspective, the use of DALYs and QALYs in triage decisions discriminates against and excludes people with disabilities, as it allocates scarce resources based on ableist value judgments about people's quality of life, rather than on evidence. From the point of view of equity, it may imply and reinforce structural injustices involving inequities, that is, avoidable or remediable inequalities. This analysis will argue that the use of DALYs and QALYs categories in triage decisions allocates potentially life-saving resources based on ableist value judgments that lead to an unfair distribution of risks, burdens, and costs. Finally, two objections related to the relevance or necessity of using these or similar categories as criteria will be addressed: the independent cases of structural inequities and the relevance of patient functional status to maximize lives saved.

**Keywords:** Disability Adjusted Life Years; Quality Adjusted Life Years; Triage; Equity; Queer-Crip Perspective.

## 1. Introduction

During the early months of the COVID-19 pandemic, some institutions and committees have recommended, directly or indirectly, the use of Disability Adjusted Life Years (DALYs), Quality Adjusted Life Years (QALYs), or "functional status" as priority or tie-breaker criteria<sup>3</sup> in triage decisions<sup>4</sup>. In the United States, some disability rights groups quickly complain about the recommendation from several guidelines distributed by state agencies of referring hospital patients with "loss of energy reserves, physical capacity, cognition, and general health" to outpatient or palliative care, rather than providing them with some of the scarcely available and

potentially lifesaving resources, such as respirators, hospital beds, stretchers or energy systems (DISABILITY RIGHTS WASHINGTON, 2020)<sup>5</sup>.

DALYs and QALYs combine the quality of life and the length of life into a single index measure that allows comparison of different health interventions and are often used in health economics studies and health technology assessment (ORTIZ AMEZQUITA & PLATA CASTILLO, 2011; THIERER, 2019; NICHSR, 2016)<sup>6</sup>. The value of DALYs results from the combination of the remaining years of life a person with a certain level of disability (YLD) and the years of life lost (YLL), i.e. premature mortality according to global or local average life expectancy (WHITEFORD ET AL., 2013). In other words, each DALY is equal to YLD plus YLL. Thus, the lesser the presence of disability and the fewer years of life lost, the lower the rate of DALYs, which is positively valued, e.g. in implementing public policies that reduce DALYs (BORRUEL, MAS, & BORRUEL, 2010). The value assigned to each year lived with a disability presupposes the use of the value unit "disability", which is determined from a table of values assigned to different levels of difficulty in performing activities of daily living (MATHERS, LOPEZ, & MURRAY, 2006; MURRAY, 1994). This means that a higher requirement of support from other people (e.g., eating or bathing) results in a higher rate of disability. This general table is then translated into different psychophysical conditions of the International Classification of Functioning, Disability and, Health (ICF) of the World Health Organization (WHO, 2001). Once the specific weights of certain relevant conditions are available, these values are applied to the calculation of the DALYs for each patient<sup>7</sup>.

In turn, QALYs weigh the number of remaining years of the life of a person with the future quality of life. This category has an inverse valuation to the previous one, as it is positively valued not its reduction but its increase (ALVIS & VALENZUELA, 2010). In QALYs, the value unit "quality" is obtained from surveys such as the EQ-5D<sup>8</sup>, commonly used in Argentina and Chile (AUGUSTOVSKI ET AL., 2018), but also in Spain (MSSSI<sup>9</sup>, 2014). The modality of this type of survey is varied, ranging from counterfactual questionnaires to "tick-box" statements about one's situation. These surveys aim to find out about people's need for care and psychophysical pain, as well as their assessment of their quality of life, with the assumption that there is a direct relationship between these variables. These surveys are then surveyed and quantified into values assigned to different ICF conditions, and finally, lead to QALYs.

While DALYs and QALYs may be relevant for assessing the introduction of new technologies in comparison to older ones, as well as public health investments and prevention, they "would present ethical and legal problems" in other contexts such as triage during public health

emergencies (EMANUEL ET AL., 2020, 2052). In this paper, we will argue that the use of DALYs and QALYs as priority or tie-breaker criteria for the allocation of scarce unallocated therapeutic resources in triage decisions is not ethically permissible<sup>10</sup>. To do so, we will draw on theories framed within a queer-crip perspective and ethical equity frameworks. From a queer-crip perspective, the use of DALYs and QALYs in triage decisions unfairly discriminates against and excludes people with disabilities, as it allocates scarce resources based on ableist value judgments about people's quality of life that are ethically and empirically unsupported. These judgments are characteristic of the so-called "standard view of the quality of life of disabled people" (AMUNDSON, 2005), hereafter referred to as the "standard view of disability". From the point of view of equity, it implies and reinforces inequities and/or structural injustices involving avoidable or remediable inequalities in the distribution of risks, burdens, costs, and access to health. Moreover, the slowness or inefficiency in obtaining all relevant data for the calculation of DALYs and QALYs for each patient implies technical or instrumental reasons to reject them as criteria during such a pandemic or other public health emergencies (EMANUEL ET AL., 2020; ROSENBAUM & CDC ETHICS SUB-COMMITTEE, 2011). However, this paper will focus on the ethical analysis for not using DALYs and QALYs because technical or instrumental reasons can be easily trumped with more resources and/or better technical means e.g., the use of partial or full automated calculation of DALYs or QALYs based on digitalized patient records.

### *1.1 Preliminary Explanations*

Before continuing, it is useful to introduce some preliminary clarifications. First, we use the notion of "queer-crip perspective"<sup>11</sup> to refer to those theoretical and methodological positions that investigate the connections between ableism and heterocisnormativity<sup>12</sup> to expose how bodily and psychic functioning, as well as gender and sexuality, are produced in unequal social conditions that fix a certain functional and sexual ideal, while defining alternative attributes as deficiencies (KAFFER, 2013; MCRUER, 2006; PÉREZ, 2019). Based on a (de)constructivist and performative conception of identity (PÉREZ, 2021)<sup>13</sup>, these approaches understand the body and its functions as a consequence of a historically specific network of power relations that encompasses, constitutes, and is constituted by a complex web of "discourses, technologies, identities, and practices that emerge from medical and scientific research, government policies and administrative decisions, academic initiatives, activism, art and literature, dominant popular culture, etc." (TREMAYN, 2017, 22). From this

perspective, differences in bodily and psychic functioning, gender, and sexuality result in injustice because of the effects of power devices that dichotomously classify people and assign them asymmetrical positions “according to regulatory ideals about body structure, appearance, movement, communication, emotional expression, etc.” (SANMIQUEL-MOLINERO 2020, 7)<sup>14</sup>. So disabled people, like other social groups, become distinguishable to the extent that social categories exist that make individuals possible and intelligible through a dichotomous lens of ability and disability and normality and abnormality (HUGHES, 2005). This does not mean that functional differences are not real, but rather, that, regardless of their ontological status, they are constructed and made intelligible as identity or subjectification categories through the mediation of specific power devices (YARZA DE LOS RÍOS ET AL., 2019).<sup>15</sup> In this sense, the available medical, identitarian, and ethical categories in a certain historical and cultural context constitute the constrictive scenario in which bodies are thought of and compared (BUTLER, 1993).

Secondly, we use the expressions “disabled people” and “people with disabilities” in a broad sense, i.e. they denote those people with one or more of the conditions traditionally labeled as “disabilities”, such as “Down syndrome, cerebral palsy, achondroplasia, spina bifida, autism, blindness, deafness, paraplegia, and quadriplegia”, among others (S. M. CAMPBELL & STRAMONDO, 2017, 153). In this article, these expressions are used in an operational sense, and not an identitarian sense. So, they try to delimit the mentioned social group without considering that it is this expression that people use to identify or to self-perceive. Accordingly, “disabled people” and “people with disabilities” are used as a “semantic bell” or “semantic umbrella” that encompasses other terms in circulation<sup>16</sup>.

Finally, we consider it necessary to bear in mind that our aim in this article is to show that the application of DALYs and QALYs in triage decisions reinforces ethically impermissible ableist social standards and structural inequities. Thus, we do not intend to answer the relevance, justification, or usefulness of DALYs and QALYs indexes in other relevant contexts (DRUMMOND ET AL., 2015). Furthermore, while the context of this paper and much of the cases and data collected are specific to the COVID-19 pandemic, the arguments presented here pretend to go beyond the boundaries of the recent pandemic.

## **2. Ethical Queer-Crip Considerations**

The categories of DALYs and QALYs are often presented as opposing units of measurement, as it is desirable to reduce the former but to increase

the latter (ALVIS & VALENZUELA, 2010; LEE ET AL., 2017). However, arguing that the presence of disability over a period implies a lower quality of life is highly questionable, especially since this argument establishes a direct and not-contextual correlation. As we will show below, empirical evidence sets up that this correlation is, in most cases, incorrect.

### *2.1 Quality of Life and the Standard View of Disability*

Several studies have shown that external judgments about the quality of life of people with disabilities carry negative identity prejudices in at least two ways<sup>17</sup>. First, they close the symbolic and material possibilities of the future for the social group included. Second, they produce and are produced in a system of structural oppression called "ableism" (ARNAU RIPOLLÉS, 2014; F. K. CAMPBELL, 2008; SHAKESPEARE, 2006; WOLBRING, 2008). In short, ableism is

a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life. (UNITED NATIONS, 2019, 3)

The appraisal of people's quality of life-based on these stereotypes culminates in Standard View of Disability (SVD). Such a view understands disability as intrinsically, not about its effects, and inevitably, independent of the context, disadvantageous, thus worsening the quality of life of people who have it, and it would even be advisable to eliminate it from the human experience (AMUNDSON, 2010; S. M. CAMPBELL & STRAMONDO, 2017; WIESELER, 2020). SVD is a specific way in which common sense is expressed about the quality of life of people with disabilities, sometimes at the expense of their own testimony. Under this conception, a person with a given disability invariably has a worse quality of life than if he or she did not have the disability. In a stronger version, this position argues that disability has very strong negative impacts on a person's quality of life, so it is presented as a determinant and privileged factor. In this sense, although the relationship between the belief that disability is a determining disadvantage and the devaluation of the lives of people with disabilities is not direct, the former belief often reinforces aspects of pity and compassion, proper to a discriminatory model that devalues this social group (AMUNDSON, 2005). In the case of the early period of the COVID-19 pandemic, SVD influence in triage decisions involved the risk of devaluing the lives of people with disabilities because of the assumption of their poorer

quality of life and thus depriving them of respirators, hospital beds, stretchers, or energy systems (DISABILITY RIGHTS WASHINGTON, 2020).

The exploration of how DALYs and QALYs are obtained and calculated is crucial to explain, on the one hand, the connection usually established between disability and lower quality of life and, on the other hand, the use of these measures as triage criteria. In DALYs, the value assigned to each type of disability corresponds to the level of assistance or support required to perform various activities of daily living. Higher degrees of assistance or support requirements are interpreted as "an evil to be minimized" (BURDILES & ORTIZ POMMIER, 2021, 70). If this conception is applied to the allocation of scarce resources, this minimization might involve excluding people with higher DALYs. In the case of QALYs, the value of quality of life is obtained from surveys that inquire into parameters of independence, efficiency, and productivity. Although the latter method claims to incorporate the subjective opinion of each respondent, during implementation these surveys are taken as "public opinion" and are established as representative assessments of the population's wishes.

However, as Hausman argues, the intuitive comparisons made by respondents not only are uncertain, subject to framing effects, and differing between individuals and social groups, but also "the value of health states will depend profoundly on individual goals, tastes and circumstances, rather than exclusively on the mental and physical state of individuals" (HAUSMAN, 2012, 233). A queer-crip perspective allows us to understand that most of the intuitions of the responders are informed by the social aspiration to lead a self-sufficient life independent of other people and social supports. This social aspiration is a product of power dynamics that have established a proportional relationship between health, normality, and an "able" and "self-sufficient" body (MCRUER, 2002; PÉREZ, 2019). That many people wish not to have a disability is not evidence that having a disability invariably worsens the quality of life, but rather of the effectiveness with which these regulatory ideals operate.

These implicit assumptions in the value assignments of DALYs and QALYs are closely linked with SVD. The regulatory ideas of independence and self-sufficiency as positively valued characteristics are the counterpart of thinking of disability as a disadvantage in a person's quality of life, and care and social support requirements as signs of weakness<sup>18</sup>. But this common sense point of view is highly supported by philosophy, academia, and bioethics too<sup>19</sup>, and underpins a multiplicity of practices relevant to contemporary life, such as the allocation of budget for genetic research in the service of prevention or reduction of disabilities, selective abortion on fetuses with certain genetic conditions, the exclusion of disabled people

from medical care, the attitude of pity directed towards them, among others (S. M. CAMPBELL & STRAMONDO, 2017).

However, SVD, which identifies disability with suffering, pain, and/or illness, is false. First, because empirical evidence shows that in appropriate environments<sup>20</sup> people with disabilities have rated their quality of life similarly or just below the average of the general population (ESCAJADILLO DAVALOS ET AL., 2020; VALLEJOS GARCÍAS ET AL., 2016; VERDUGO ET AL., 2012; WASSERMAN ET AL., 2016; WIESELER, 2020). This gap between what common sense dictates about the quality of life of disabled people and what people themselves testify has been called the "disability paradox" (ALBRECHT & DEVLIEGER, 1999). However, as recent international reports have recognized, the refusal to acknowledge the validity of the testimony of people with disabilities about their own quality of life is attributable to unintentional biases. Thus, "fear, ignorance, and prejudices permeate the understanding of the disability experience, a process that is constantly reinforced by dominant cultural representations of disability" (UNITED NATIONS, 2019, 4).

Second, those who argue that disability causes suffering because it prevents the enjoyment of certain goods, such as "appreciating a picture" in the case of blindness, fail to consider that such people enjoy multiple other goods that make their lives equally desirable (STRAMONDO & CAMPBELL, 2020). How we choose between which goods we wish to acquire, and which we do not, are influenced by cultural and contextual factors, and to accuse disability of causing suffering by preventing some of these is highly biased.

Finally, the association of disability with pain and disease is contingent and depends solely on each specific condition. Multiple types of disabilities do not involve pain or the presence of any associated disease (S. M. CAMPBELL & STRAMONDO, 2017; WASSERMAN ET AL., 2016). Even in cases where this happens, medical treatments in combination with appropriate environments often allow for an acceptable transition. Even so, we consider that pain, mainly severe and chronic pain, is an acceptable variable for assessing a person's quality of life. Despite this, in the calculation of DALYs and QALYs, the assessment of "functionality" tends to have the same, or even higher "weight", as the severity or chronic nature of the pain produced by a given disability (BORRUEL, MAS, & BORRUEL, 2010). At the same time, we find many cases of disability that do not meet this requirement and, despite this, are considered to intrinsically and invariably worsen the quality of life in the calculation of DALYs and QALYs, such as blindness or deafness.

In this sense, these arguments do not attempt to demonstrate that there are absolutely no cases of disability that could contribute to a lower quality of life, but that quality of life is composed of multiple social, economic, cultural, and personal background conditions. In addition, the acquisition of a disability often results in changes, sometimes profound, in a person's life, so that it may affect his or her quality of life temporarily until the person and his or her environment can adapt. However, the generalities of DALYs and QALYs do not consider these influences but privilege disabilities as determinant factors and take exceptional and socially isolated cases as paradigmatic for their value judgments.

As we will show below, the use of DALYs and QALYs in triage decisions is not ethically justifiable even in cases where the presence of disability leads to suffering, pain, illness, or worsening quality of life. Alternative ethical guidelines for COVID-19 triage decisions that do not take into account DALYs and QALYs exist and they usually follow a general but not unique mandate to maximize the number of human lives saved (RIVERA LÓPEZ ET AL., 2020). As Rivera Lopez et al. clarify, this general mandate is not one of an unconstrained maximization that may enable by other means the reinforcement of structural injustices, but "must be interpreted in light of human rights principles and therefore must incorporate additional restrictions that guarantee conditions of equality, reciprocity, and equity" (RIVERA LÓPEZ ET AL., 2020, 46), in this case, restrictions to maximizing the probability of human lives saved to avoid inequities towards disabled people.

## *2.2 Performativity and Compulsory Able-bodiedness*

The SVD influences how disabled people are perceived and has an impact on how they perceive themselves. The consciousness of one's own body, particularly of socially disadvantaged people, occurs through the "gaze" of "the other". In other words, it is "a third-person consciousness" (FANON, 1986, 110). Through individual and institutional practices, "society systematically sends degrading and dehumanizing messages about their appearance, behaviour and worth, which can distort disabled people's perceptions of themselves and their worth" (UN, 2019, 4)<sup>21</sup>. In DALYs, the reinforcement of negative identity stereotypes is produced by assigning value to the quality of life according to the difficulty to perform daily activities independently and efficiently. Therefore, if in the information tables measuring the value "disability", the "need for assistance in daily activities such as eating, personal hygiene, and dressing" has a score of 0.92, and the category immediately following is "death" (BORRUEL, MAS, &



BORRUEL, 2010; MURRAY, 1994)<sup>22</sup>, the negative weight of disability is presented as self-evident.

The fit between language and the world is not only from the world to language, in its descriptive function, but also from language to the world, in its performative function (AUSTIN, 1975). Thus, these measurements have a performative effect both on people who see their quality of life as necessarily inferior and on those who benefit from these scales.

This performative aspect of linguistic utterances cites and recreates norms that shape identities through their constant repetition, making what they say the only way of thinking about and imagining such identities (BUTLER, 1988; 1990). Documents such as the global burden of disease often reduce health to its individual aspect<sup>23</sup>. They define it as the "functioning capacity in a set of health domains such as mobility, cognition, hearing and vision" (WHO, 2008, 31). Given that definition, "the term disability refer to loss of health" (2008, 31). In these cases, the linguistic act implies a performative aspect since, given an ableist social context that only contemplates one form of bodily functioning, the implementation of the measurements and results entail the risk of reproducing the social belief that identifies a healthy and quality life with a life *without* disability. This imperative is crystallized in what from a queer-crip perspective is called "compulsory able-bodiedness", that is, a regulative ideal that understands the body as a machine, with parts that function in a certain way, and which is presented as the "natural" body and, by the way, the "normal" body (MCRUER, 2002)<sup>24</sup>. In our societies, these standards have an enormous influence on the population, given that they are enabling conditions for the realization of the rest of social aspirations, such as access to education, health, and paid work, to be a subject and object of desire, to be recognized as an epistemic subject, etc. (WARNER, 2000).

With this in mind, measuring a person's health concerning his or her "inability to perform [every day] activities", as stated in the survey that determines "Health-related Quality of Life" (SER, 2015), correlates the notion of "healthy living" with that of "independent living". The clearest example is in the "Personal care" section. The first option describing one's situation is to have no "problems with personal care", while the next is to have "some problems washing or dressing myself". Under these suggestive questions, "problems" appear when the person is dependent on others, which in principle has no direct relationship with their health or quality of life. The surveys that result in QALYs often oscillate between ambiguous questions, where it is indistinguishable whether one asks about the possibilities provided by the social environment, the ability to perform activities without assistance, or the effectiveness with which they are

performed. This ambiguity leads to common sense interpretations permeating the statistics and resulting in people's quality of life being measured in terms of their health, and their health in terms of the degree of "dependency" in their daily activities. Thus, uncritical acceptance of the connections between "high quality of life" and "healthy living", and of "healthy living" with "independent living", coupled with confidence in the measurability of quality of life and the methods for calculating it, reinforce SVD and unjustified negative identity biases about people who require support from others<sup>25</sup>, while accentuating the social imperatives of compulsory able-bodiedness.

### **3. Ethical Equity Considerations**

In the COVID-19 context, some recommendations and guidelines from triage professionals have suggested excluding patients with certain health conditions, such as severe cognitive impairment, from potentially lifesaving resource allocation based on the selective application of criteria related to long-term prognosis or functionality (WHITE & LO, 2020). More specifically, SEMICYUC proposed among its criteria to prioritize the combination of longer life expectancy with quality of life and, in older people, to prioritize those with "disability-free survival" (2020, 11). These recommendations have already been questioned for their tendency to "minimize costs and investment expenditure in healthcare but also for considering the value of human beings in terms of their productive capacity" (GARCÍA ORTIZ, 2020, 378) as well as for being "selectively applied only to some types of patients" (WHITE & LO, 2020, 1773).

#### *3.1 Structural Injustice*

The use of such selective criteria to justify the exclusion of certain types of patients, with DALYs and QALYs as paradigmatic cases, constitutes a practice that feeds back into structural injustices. According to Young (2006), unlike transactional exploitation<sup>26</sup>, structural exploitation systematically and unequally restricts the options for the action of the types of actors involved in a given social process, be it commercial, educational, health, or political participation. Structural exploitation is thus produced by systematic practices that increase the probability, for certain identity-marked populations, of being the object of transactional exploitation (HOLZER, 2020). This approach understands that social injustices do not consist of a deviation from institutional norms, but that, on the contrary, it

is precisely some of the socially accepted and considered “normal” basic conditions that are not morally acceptable (YOUNG, 2011).

In this sense, the structural injustice perpetrated on people with disabilities, and fed by the SVD, guarantees pervasive exploitation in their social interactions. Thus, this social group must systematically face an inequitable sum of risks, burdens, and avoidable costs to access the same resources and opportunities as other populations. As recent international reports show, access to health services for disabled people involves, in many cases,

the segregation, institutionalization and deprivation of liberty [...] in disability-specific facilities and the use of coercion based on “need of treatment” or “risk to self or to others”, the denial of legal capacity on the basis of mental capacity, the denial of treatment on the basis of disability, or the failure to consider the extra costs of living with a disability. (UN, 2019, 3)

### *3.2 Equity and Responsibility*

According to the Pan American Health Organization (PAHO), health equity is “the absence of avoidable or remediable differences among groups of people, whether these groups are defined socially, economically, demographically or geographically” (PAHO, 2020, 8). These differences perpetuate systematic unfair inequalities both in the distribution of resources and in access, permanence, and participation in the different institutions that make up a society. In consequence, “insofar as systematic inequalities in health are avoidable by reasonable means, they are unfair and hence inequitable” (PAHO, 2018, 6).

Under Young’s framework, the responsibility for health equity is justified in a social connection model. This is explained by the fact that a society “consists in connected or mutually influencing institutions and practices through which people enact their projects and seek their happiness, and in doing so affect the conditions under which others act, often profoundly” (2006, 105). In this sense, responsibility for the situation of others lies in the fact that institutional and individual decisions take place in a system of social cooperation that influences each other, even when direct causality is not easily identifiable. Hence, social actors, and notably those with greater agency, “bear responsibility for structural injustice because they contribute by their actions to the processes that produce unjust outcomes” (2006, 119). The global distribution of vaccines in 2021 has shown that, in the absence of an ethical framework that assigns global

legal responsibilities, the profitability of the entities that research and produce drugs and treatments is prioritized over global health equity (AMNESTY INTERNATIONAL, 2021; CHUNG ET AL., 2021).

Under this social connection model, personal rights, such as equitable access to health, take on “an effective normative meaning insofar as people inevitably maintain [social] relations of mutual influence” (MAREY, 2011, 159). Such relationships of reciprocal influence position us as vulnerable subjects to the decisions of others and demand public and private institutional responsibility for the situation of those they affect. Therefore, personal rights must “shift to the political, to emphasize that the social inequality to which people with disabilities are exposed is a structural issue and not a matter of individual responsibility” (MALDONADO RAMÍREZ, 2020, 49).

This analysis allows us to understand that the SVD twists ideas of interdependence and responsibility, as obtaining support is interpreted as a source of humiliation, shame, or lower quality of life. If we consider its influence on the calculation of DALYs and QALYs, the use of these categories in triage decisions during COVID-19 leads to avoidable or remediable structural inequities in the distribution of risks, burdens, and costs, as it takes empowering value judgments as justification for inequitably allocating potentially life-saving resources. This tends to feed back into pre-existing relationships of inequity, structural injustice, and evasion of responsibility among the various social actors.

The tendency of bioethical debates to develop triage protocols in isolation from broader political discussions about pre-existing structural injustices is therefore problematic. The deliberation on building medical and social responsiveness to reduce structural injustices and avoid triage decisions has become secondary (TREMAIN, 2017). In this context, the fact that bioethicists take triage protocols as the main object of analysis “seems to sanction the idea that these hard choices are inevitabilities” (STRAMONDO, 2020). Thus, situating health decisions in a context of underfunding of the public health system, increasing informal work and the erosion of basic service infrastructure allows us to recognize that the arrival of triage decisions means that many other social guarantees have failed. Given that, it is ethically impermissible to trade the lives of the most vulnerable people for the profits of public and private institutions. Professional bioethics must be concerned not only with triage protocols, but also with the “end to the kinds of large scale, systemic injustices that are hindering our ability to minimize the amount that triage will be necessary” (STRAMONDO, 2020).

## 4. Objections

We consider it necessary to contemplate some possible arguments that challenge the hypothesis of this article and suggest that the use of DALYs and QALYs in triage decisions might be ethically permissible in some cases. In the following, we will develop two objections followed by their possible responses:

### 4.1 *Objection 1: Independent Cases of Structural Injustices*

A first objection is that certain unavoidably disadvantageous conditions must be considered when calculating QALYs and prioritizing patients with equal chances of survival, such as those that make experience impossible, agency impossible, or cause severe chronic pain. Assigning lower priority in the allocation of scarce resources to people with lower QALYs may be worse for them, but does not deepen structural injustices, but rather recognizes a fact (PERSAD, 2019).

To respond to this objection, we will assume that health professionals have the capacity and the tools to distinguish inevitably disadvantaged conditions from conditions of social disadvantage. One possible response to this objection is that even if some people's lives were worse for reasons unrelated to unjust social factors, applying priority criteria based on the quality of life multiplies the harms already present and is therefore ethically impermissible. This practice constitutes a double harm, in that the inevitably disadvantageous condition, by which a person is interpreted as a victim, serves as a justification for being a candidate for a second event that amplifies their disadvantage, as the use of QALYs in triage gives them little or no chance of benefiting from life-saving treatment. Thus, a first event leaves her with a poor quality of life, and a second event finishes her off (HARRIS, 1987; SEN, 2002).

Second, we consider that external judgments about the value of life are irrelevant to triage decisions. While the use of QALYs is most compelling when the same individual must choose between two treatments that offer different quality of life, "when the same approach is used to decide which of two people to treat, however, then important distributional concerns arise" (HELLMAN & NICHOLSON, 2021, 44). The debates surrounding triage decisions during COVID-19 are not about reducing those conditions that are inevitably disadvantageous because they are undesirable, but about prioritizing some people over others. In this context, arguing that those with less harmful conditions should be prioritized over those with more harmful conditions is not an adequate justification, even when QALYs

surveys explicitly state that one life is socially more desirable than another. Social desirability and third-party judgment have little to contribute to the debate about the priority of some lives over others (STRAMONDO, 2021).

#### *4.2 Objection 2: Relevance of patient functional status to maximize lives saved*

A second possible objection is that disregarding consideration of the functional status of possible candidates for a potentially scarce lifesaving resource would imply a failure to recognize that there are patients who will require a greater quantity of resources than others. For example, a person with lower mobility than another may be expected to require hospital beds, stretchers, or health care workers for a longer period. This non-recognition would go against the maximized lives saved criterion. Allocating scarce health resources to people who will make greater or longer use of them is an inefficient allocation. In consequence, for patients with the same probability of survival, the level of resource intensity is an acceptable priority criterion (ROGERS & CARTER, 2020). Sometimes some forms of discrimination may be exceptionally justifiable in the context of a health crisis, such as during the COVID-19 pandemic.

One possible reply to this second objection is that, although the level of resource intensity criterion is efficient in maximize the number of lives saved in the allocation of scarce health resources, rejecting such a criterion does not imply an unjustified waste of resources (BALLENTYNE, 2020). In this sense, we agree with Stramondo (2021) that in cases where there are patients who require greater resources than others, or than the average, to survive, it is advisable to discard the distinction between efficiency or inefficiency and think about the triage in terms of success or waste. In this context, "inefficiency implies that a resource was not used to achieve its maximum benefit. Waste implies that a resource was not used to achieve any benefit" (2021, 205). Thus, allocating greater resources to certain patients may be inefficient, but this does not imply that those resources have been wasted, as survival has been a success.

Furthermore, the WHO argues that "despite the importance of conserving limited resources, the ethical principle of equity may sometimes justify providing greater resources to persons who have greater needs" (2016, 18). Since persons with disabilities are the population that most assume the burdens of discrimination based on functional status, the use of the level of resource intensity criterion in triage could constitute a double harm. In consequence, in cases where inequalities are pronounced and long-standing, "it may be fairer to give preference to groups that are worse

off" (WHO, 2016, 21). In this sense, discarding the level of resource intensity criterion means saving fewer lives, but it also means considering structural inequities and contributes to a fair use of scarce resources (Ballantyne 2020).

Secondly, it is relevant to note that the rhetoric that has presented COVID-19 as "a common enemy" (AIDS HEALTHCARE FOUNDATION, 2021) has contributed to equalizing social groups in terms of vulnerability and responsibility. However, this process has taken place in merely discursive terms and the sectors of the population most affected during the COVID-19 pandemic have been the same as in previous periods (UNITED NATIONS, 2020). The rhetoric of crisis has presented the social problems as something passing, which detached them from the connections with the social and historical context, and promoted the justification of emergency measures such as disciplining, repression, control, coercion, or passive eugenics, which are unlikely to be reversed (PÉREZ, 2020). The excessive and institutionally legitimized demand to postpone comprehensive and long-term measures to effectively diminish the impact of COVID-19 allowed social inequalities to be accentuated and transferred to the impact of the pandemic.

## 5. Conclusion

The proposal and use of DALYs and QALYs as triage criteria for COVID-19 patients have initially been presented as an adequate response to the urgency of the "health crisis". However, on the one hand, these categories are implicitly constituted by ableist prejudices framed within the SVD, and on the other hand, they are applied without an analysis of the social context and the structural conditions that precede them. Since the influence of this view on a wide range of important practices in contemporary life, it produces performative effects on the population and becomes a social imperative of compulsory able-bodiedness.

When the SVD serves as a hidden justification for excluding people with disability from access to potentially life-saving resources, this situation feeds back into structural injustices that reiterate and systematize instances of exploitation directed towards this social group, in violation of the ethical duties of equity and responsibility.

As a final reflection, we consider that only when disabled people are no longer excluded from the spaces of political participation and institutional decision making, then their claims for their rights will be heard, as "stakeholder engagement proved an effective avenue for modifying policies that were previously the exclusive domain of experts" (NE'EMAN ET AL.,

2021, 856). Although many of the protocols mentioned here have already been revised, the Economic Commission for Latin America and the Caribbean (ECLAC) reported that “more than 40% of COVID-19-related deaths during 2020 occurred in long-term care facilities”, whose users are largely people with disability (2021, 13). In the notable case of the United Kingdom, almost 60% of COVID-19 deaths during 2020 have been among disabled people, an alarming finding given that they constitute only 17.2% of the total population (FORREST, 2021). This differential effect is directly related to the position these people occupy in society and to pre-existing inequities in health and social care (HAMILTON, 2021). The importance of this paper lies not only in responding to the distribution of scarce resources during COVID-19, but also in providing arguments to prevent and address future public health emergencies so that responses to urgent problems do not impede profound social transformation.

## Notes

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<sup>3</sup> Prioritization criteria have the role of selecting certain patients as preferred candidates over others to receive a potentially scarce lifesaving resource. Given the possibility of patients in full parity for such criteria, it is possible to consider tie-breaker criteria, which supplement priority criteria for final decision making (RIVERA LÓPEZ ET AL., 2020). Despite the difference, the arguments used in this paper are intended to work in both cases.

<sup>4</sup> Examples include the Spanish Society of Intensive and Critical Care Medicine and Coronary Units (2020), the Washington State Department of Health (2020), the National Bioethics Committee of Pakistan (2020) and the Australian and New Zealand Intensive Care Society (WARRILLOW et al., 2020).

<sup>5</sup> The full list of complaints and responses can be found at the following link: <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.

<sup>6</sup> As the National Information Center on Health Services Research and Health Care Technology (NICHSR) states that “one of the main reasons for using such [...]”



measures is to enable comparisons of the impact of health technologies or other changes (e.g., environmental or economic) where the outcomes (other than survival) are not the same, e.g., incidence of diabetes, reduction in heart attacks, or prevalence of tobacco use" (NICHSR, 2016).

<sup>7</sup> For example, living a year with blindness, *Ceteris paribus*, represents a higher loss of health and quality of life than living a year without blindness. In this case, the person loses 0,43 of health value per year of life (MATHERS, LOPEZ & MURRAY, 2006). If two persons have the same prognosis for remaining years of life, e.g., 20 years, and their YLL is 0, the DALYs score of the person with blindness is 8,6 [(20x0,43) + 0], while the score of the person without blindness is 0 [(20x0) + 0].

<sup>8</sup> A copy of the Spanish Society of Rheumatology survey is cited (SER, 2015).

<sup>9</sup> Ministry of Health, Social Services and Equality.

<sup>10</sup> Here, it will not be dealt with the important problem, identified in the recent literature, of the ethical permissibility of relocation of already allocated therapeutic resources (ABAL, 2021).

<sup>11</sup> Taking a set of theoretical developments as a perspective implies using them not so much as a theoretical corpus but as a toolbox, an interpretative strategy, for thinking about reality (PÉREZ, 2021).

<sup>12</sup> In short, heterocisnormativity is a socio-economic regime that not only defines and regulates cultural canons of gender and sexuality, but also a whole symbolic and material order of acceptable and desirable ways of life, to the detriment of those that do not follow a pattern associated with heterosexuality (WARNER, 1991) and cisgender (RADI, 2020).

<sup>13</sup> Theories of performative constitution argue that identities are established through the stylisation of everyday bodily acts, gestures, movements and styles that create the illusion of a pre-existing and stable agent (BUTLER, 1993). If we grant that there is no original identity to refer to, then neither would there be true or false, natural or monstrous, functional, sexual or gendered acts, and the demand for a true identity would be revealed as a regulative fiction (BUTLER, 1990).

<sup>14</sup> This and the following translations of the texts quoted in Spanish are my own.

<sup>15</sup> We are grateful to one of the journal's reviewers for the collaboration with the conceptual elucidation of this paragraph.

<sup>16</sup> For a more precise approach to the "operational use" of a category, see Radi (2019).

<sup>17</sup> Identity prejudice is a systematic way of representing a social group on the basis of cultural stereotypes present in the collective social imaginary (FRICKER, 2007).

<sup>18</sup> Consider that the current cultural category of disability emerged in a context of mass production of goods and services during the First European Industrial Revolution. Thus, the demand for useful, productive, and employable individuals resulted in the discarding of individuals "non-able" to contribute efficiently to this type of work (OLIVER, 1998).

<sup>19</sup> See Davis (2009), Glover (2006), Kahane y Savulescu (2012), or Singer (2009).

<sup>20</sup> We use the expression "appropriate environment" to refer to a non-disabling social context. Disabling conditions are those that present barriers to a particular social group in relation to "full participation in society and the recognition, enjoyment or exercise of human rights and fundamental freedoms in the civil, political, economic, social, cultural or other spheres" (PALACIOS, 2008, 317). Such barriers can be legal, attitudinal, architectural, communicational, among others, and are often informed by a social structure designed for a specific body type.

<sup>21</sup> For an in-depth discussion of the ways in which social classifications have consequences for the lives of people who are categorized, see Hacking (1999).

<sup>22</sup> The negative weight assigned to death is traditionally understood under the conceptualization of '*deprivation account*', i.e. as deprivation of positive future goods and experiences (MILLUM, 2019; MOGENSEN, 2019).

<sup>23</sup> Although the mentioned study does not explicitly state that health is an individual condition, the measures used there assess health conditions with insufficient considerations of the relation disease-environment. Thus, in their implementation, the concept of "health" hardly considers the human relationship with the possibilities offered by the social context, and it is usually confined to the individual or biological level.

<sup>24</sup> For an in-depth approach to the connection between natural and normal, see Canguilhem (1978), Fausto-Sterling (2000) and Foucault (1994; 2003).

<sup>25</sup> Although not the focus of this article, the idea that is underlying this argument is one that the very division between people who require support and people who do not is problematic. Butler understands that interdependence is not a passing or alterable state, but a condition of vulnerability that coexists with our existence as human beings, as it names our way of relating to the world. Recognizing ourselves as vulnerable implies accepting "our fundamental dependence not only on others, also on a world that sustains and sustains us" (2014).

<sup>26</sup> Mutually advantageous transactional exploitation occurs when in an exchange or transaction between two agents, the exploiting agent is unfairly advantaged to the detriment of the exploited agent's benefits.

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