Discriminatory Nature of Quality Adjusted Life Years:
Especially during the COVID-19 Pandemic

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

Beyond the worldwide panic that ensued after the outbreak of the COVID-19 pandemic in the US in March 2020, the shortages in protective and medical equipment caused further panic in the medical community (Ranney et al., 2020). Europe faced shortages in hospital beds and Americans worried that they would be similarly inundated. Since COVID-19 is a respiratory virus, mechanical ventilators became an integral part of treatment, but reports indicated that the US would need an additional 60,000-160,000 mechanical ventilators if it was to see the same hospitalizations rates as Europe.

In response to the need for mechanical ventilators Ventis Medical was founded in March 2020 with the goal of creating a ventilator that was more accessible to both providers and patients. The ventilator, the VM-2000, was less expensive, smaller and easier to use than its competitors. The company hoped to remove the need for medical rationing during the COVID-19 pandemic by making mechanical ventilation, a major part of a COVID-19 treatment plan, more accessible. However, since the pandemic is largely over, Ventis Medical has shifted its focus to making the VM-2000 compatible with emergency situations. The capstone project associated with this ethical thesis is to integrate a mask attachment to the VM-2000, making it capable of non-invasive ventilation.

Because of the massive shortages of medical equipment that the US faced as a result of the COVID-19 pandemic, the topic of medical resource rationing was a subject of much debate. Governments were forced to put protocols into place that would prioritize who received available equipment. Many of these protocols came from “ Crisis Standards of Care” (CSC) put in place following the Swine Flu Pandemic in 2009. Unfortunately some of these standards were blatantly discriminatory toward those preexisting mental and physical disabilities. In theory these new protocols would give the most ill people access to any equipment necessary, however it inadvertently excluded those with physical disabilities. Because many protocols gauged a patient's level of illness compared to their life before contracting COVID-19, those who were physically disabled prior to infection would not see a drastic change in physical ability. As a result, they were passed over for medical equipment (Chen & McNamara, 2020). Learning about these examples of discrimination forced me to wonder if there are other, seemingly good intentioned, treatment standards that actually discriminate. I had previously studied quality adjusted life years (QALYs) in class and the medical equipment rationing seemed similar. This thesis will answer the question: **do quality adjusted life years discriminate against those with physical disabilities, and if so, how?**

Methodology

Using a series of reports from the National Council on Disability, as well as a historical review of QALYs have been able to better understand how QALYs have affected those with disabilities and especially during the COVID-19 pandemic. This paper will attempt to explain how QALYs were developed and why they are inherently discriminatory. It will also attempt to address how QALYs may violate the Americans with Disabilities Act.

Results

What are QALYs and how are they determined?

Quality adjusted life years (QALYs) are an economic metric of a person's life. The metric attempts to quantify how a treatment protocol, drug, procedure or disease will affect an individual.

It is meant to take both quantity and quality-of-life into effect. It compares a panel of healthy individuals to the potential outcomes of the treatment that may be given. A graphical representation can be seen in Figure 1.

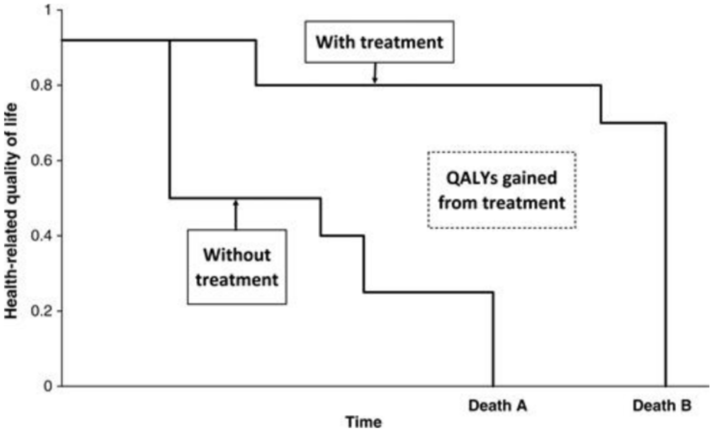


Figure 1: This figure is a graphical representation of QALY. Space between the two lines is the potential life gained with medical intervention.

The origin of QALYs is disputed, however they were developed to quantify the economic effect of new medical technology of the 1960s and 1970s, such as organ transplants and dialysis, especially as the cost of medicine was growing rapidly (MacKillop & Sheard, 2018). British economists Tony Culyer, Bob Lavers, and Alan Williams combined the already established quality-of-life assessments with the cost of the treatment and severity of the outcomes to quantify the “undesirability” of a disease or treatment (MacKillop & Sheard, 2018). Rachael Rosser and Vincent Watts further this research by evaluating the degrees to which a hospital stay improved a patient’s life. Eventually Rosser and Williams began to work together to combine the quality-of-life analysis with their life expectancy to the QALYs. Williams is responsible for Equation 1 (Hammell, 2006; MacKillop & Sheard, 2018).

Equation 1:

$$QALY_G = T_1 Q_1 - T_0 Q_0$$

QALYs are calculated using two numbers. The first is the number of years a person's life will be extended (T). The second is the heath state (Q) (*Cost Utility Analysis*, n.d.; Hammell, 2006). A health state is a value from the general public and ranges from 0 (death) to 1 (perfect health). It is a subjective measurement that takes into account mobility, self-care, daily routine, pain or discomfort, anxiety, and depression (*Cost Utility Analysis*, n.d.). These scores come from surveys of the general population. The QALYs are finally calculated using multiplying T and Q together. For example if a treatment is to extend someone's life 6 years, but with a health state of 0.75 then the QALYs will be 4.5. Equation 1 shows the QALYs gained by subtracting the QALYs with treatment from QALYs without treatment (Hammell, 2006).

What are the typical uses of QALYs?

QALYs are primarily used by the National Institute for Health and Care Excellence (NICE) in Britain (*Cost Utility Analysis*, n.d.). QALYs were initially developed as an economic tool used in Cost Utility Analysis (CUA), also known as Cost-Effectiveness Analysis (CEA) in the US, to compare the opportunity cost of alternative medical interventions. The cost per QALYs, is the cost of a treatment per year it is extending a person's life (*Cost Utility Analysis*, n.d.; *Part V: Cost-Effectiveness*, n.d.). For example if a treatment costs $6,000 to extend a person's life by 6 QALYs then the cost per QALYss is $1,000. In England there are QALY thresholds that establish whether a treatment will be given or not. These thresholds are arbitrary and do not account for inflation over time.

In the US, QALYs have been used in Oregon and New York to determine the cost of Medicaid coverage (*Notice of Funding Opportunity*, 2021). However, in both cases the policies set using QALYs were found to violate the Americans with Disabilities Act (ADA). The National Institutes of Health and Center for Disease Control use QALYs to recommend drugs (*Cost-Effectiveness, the QALY, and the EvLYG*, n.d.). QALYs are used to determine if a patient should undergo a treatment or which treatment a patient should undergo if there are options (Loomes & McKenzie, 1989).

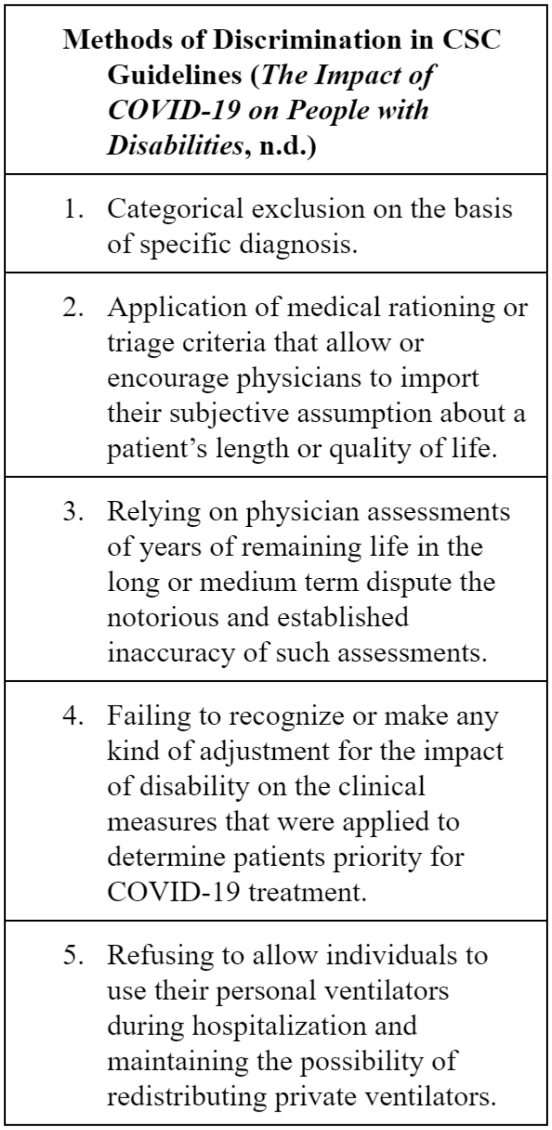
How do QALYs inherently discriminate?

QALYs have been a subject of much debate since their inception, largely because they are not regulated and because the metrics for obtaining a QALYs assessment are so variable. The health state in the QALYs assessment relies on input from the general population to assess how debilitating a disability is. In doing so this QALY fails to take into account the opinion of the disabled person (Arras et al., 2015; Bagentos, 2020). Furthermore studies have shown that 'people who acquire a range of disabilities typically do not experience…reduction in the enjoyment of life' (Bagentos, 2020).

An example of a health state metric is the EQ-5D, which uses categories such as physical, cognitive, and social functions as metrics to determine health state. The National Council for Disability argues that categorizations such as these do not take enough into consideration the perspective of the disabled person (National Council on Disability, 2019). Usual activities and relationships are examples of metrics not considered when determining health state but have an impact on an individual's quality-of-life. An example of a question asked on the EQ-5D questionnaire is: "I have some problems in walking about" (National Council on Disability, 2019). If the general population was asked this question, an answer other than no would be the result of a major life altering event and likely decrease their quality-of-life. The question does not consider people who use a wheelchair or cannot walk without the assistance of a cane or extensive physical therapy. For those who have not known anything different or who have acclimated to their disability would not find problems with walking an issue. Generally the QALYs assessment does not take the subjectiveness of its metrics into account. It does not consider that some people value less anxiety over less pain or vice versa. However, the heath states are weighted differently with the preferences of the general population (Whitehead & Ali, 2010).

How do QALYs discriminate in policy?

Table 1



Methods of Discrimination in CSC Guidelines (*The Impact of COVID-19 on People with Disabilities*, n.d.)
1. Categorical exclusion on the basis of specific diagnosis.
2. Application of medical rationing or triage criteria that allow or encourage physicians to import their subjective assumption about a patient’s length or quality of life.
3. Relying on physician assessments of years of remaining life in the long or medium term dispute the notorious and established inaccuracy of such assessments.
4. Failing to recognize or make any kind of adjustment for the impact of disability on the clinical measures that were applied to determine patients priority for COVID-19 treatment.
5. Refusing to allow individuals to use their personal ventilators during hospitalization and maintaining the possibility of redistributing private ventilators.

During the COVID-19 pandemic, both local and federal governments turned to ‘Crisis Standards of Care (CSC).’ These standards were put into place following major events in the early 2000s. Following the terrorist attacks of September 11, 2001, the government put CSC into place in fear of bioterrorism (Chen & McNamara, 2020; *The Impact of COVID-19 on People with Disabilities*, n.d.). The CSC were later updated following the Swine Flu outbreak in 2009. These standards outline how governments would respond to emergencies and how to allocate both resources and money to those most in need. The goals of the CSC was to be generalized for all crisis situations, not specific events (*The Impact of COVID-19 on People with Disabilities*, n.d.). The cases in New York and Oregon mentioned in an earlier section are examples of crisis standards that were used too liberally. During the COVID-19 pandemic guidelines use quality-of-life analysis to set standards of care for treatment and for medical equipment rationing (Bagentos, 2020).

That national council for disability released a report detailing how those with disabilities were discriminated against during the COVID-19 pandemic. Table 1 shows specific examples of discrimination of CSC guidelines include the 2011 Florida guideline that did not permit hospitals from admitting patients who require ‘lifelong assistance with most basic activities of living (i.e. toileting, dressing, feeding, and respiration)’ (*The Impact of COVID-19 on People with Disabilities*). Additionally, an Alabama guideline states that ‘persons with severe mental retardation…may be poor candidates for ventilator support’. Methods 2 and 3 create the opportunity for completely subjective analysis of how detrimental a disability may be to one's life (*The Impact of COVID-19 on People with Disabilities*). In Pennsylvania the CSC guidelines seem to focus on saving ‘life years’ instead of individuals. If a system using QALYs was applied in Pennsylvania, it would mean that QALYs were used directly to decide who receives medical treatment.

Although the CSC guidelines were not designed to be discriminatory, they open the door for discrimination by allowing people who are not affected by a disability to make general assumptions about it. Additionally, when people are categorized for treatment, the guidelines diminish the value of the lives of people with disabilities and allow the implicit bias of physicians to dictate treatment.

Because QALYs are not directly cited in United States’ laws or regulations, it is difficult to directly attribute them to the disability-based discrimination. However during the COVID-19 pandemic some CSC directly cited QALYs which opened the door for them to be struck down by the court (Bagentos, 2020). These regulations were eventually struck down because they violated the Americans with Disabilities Act (ADA) and the Affordable Care Act (Bagentos, 2020). Since the ADA prohibits discrimination against individuals with disabilities, QALYs violate it by allowing people with disabilities to be excluded from treatment.

Conclusion

The COVID-19 pandemic exposed shortages in medical equipment in the US and forced policy makers to make decisions about how the little equipment would be distributed. The protocols put in place unfortunately discriminated against those with preexisting disabilities. The metric used to make these decisions, quality adjusted life years, is an economic metric that was transitioned to more uses. Originally intended to set drug prices and quantify the worth of a medical treatment in an economy with rapidly rising prices, QALYs have seeped into the care standards for healthcare, especially in times of crisis. Because of their history in economics QALYs prioritize treatments that are the most ‘worth it’ without considering the needs or affects on people with disabilities. The subjective nature of the heath state metric in QALYs forces people without disabilities to make assumptions about how disabilities affect quality-of-life. The two reports from the National Council on Disability gave concrete examples of how QALYs and CSC discriminate against people with disabilities both before and during the COVID-19 pandemic. Fortunately most of the policy regarding QALYs outside the pandemic has been recognized as discriminatory. Access to healthcare, like everything else covered under the ADA, is a right and cannot be taken away on the basis of disability.

Word Count: 2469

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