



## **Age, dementia and the allocation of health resources during and beyond COVID-19**

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The extraordinary circumstances of the COVID-19 pandemic bring into sharp focus a fact of life that most of us ignore: that health care resources are always limited. This is very true for people with dementia and more generally for people with disabilities. They are limited by political and economic decisions concerning expenditure on medical research, drug subsidies, health care funding and so on. These long-term issues will not be resolved in mid crisis, but they are relevant to the way the crisis is handled. It is an opportunity to draw attention to longstanding issues and not give up in despair.

This article explores issues in health resource allocation, measurement of quality of life, the options open to decision makers and the importance of transparency in decision-making. There is no simple answer to complex decision making but the clear requirement is for transparent decision making in judgements that impact on people's lives. The need goes beyond guidelines that are understood and acceptable to doctors and consumers and relevant in times of crisis at the bedside to broader issues of health policy, structural and legal issues.

## Health Resource Allocation

Decisions about how to distribute limited health resources are rarely made at the bedside. They more typically occur at some steps removed from any individual patient, at the 'macro' level of funding decisions. This shouldn't obscure the fact that macro decisions very often directly impact who lives and who dies. Doctors deliver terrible news by informing patients that there is nothing more they can do for them: they are out of treatment options. What is not explained are the other causal factors that may well be contributing to a patient's death at this time: for example, the paucity of research funding for their disease, or the lack of government subsidy for a drug that could help extend their life, or the institution's practice to not offer chemotherapy for disease at this stage, or for patients with this particular profile.

In some countries, COVID-19 is bringing decisions about health resource allocation much closer to the bedside.<sup>i</sup> A shortage of health resources – intensive care beds, nurses, protective equipment, ventilators, paramedics – may force decisions that mean some people miss out on life-saving interventions. It raises difficult generational issues. How can such decisions be made ethically?

While there has been much discussion about the ethics of health resource allocation, there is very little consensus. Most people accept the need to make some kind of decisions about how we can get the most benefit from our limited resources, no less so in times of crises. The sticking point is how to understand 'benefit'.

'Benefit' is rarely interpreted in an exclusive quantitative sense, such that the most beneficial way to spend resources is toward whatever interventions extend life for as long as possible. Very few people believe such a simple quantitative approach yields satisfactory outcomes. The result would be to prioritise funding medicines and treatments that extend life irrespective of its quality. At a population level, it would mean prioritising any intervention that offered hope of some extended months of life over the vast range of interventions we rely on to dramatically improve our quality of life, such as treatments that improve functioning, or alleviate pain. In short, quality of life is an important factor to include in difficult allocation decisions. 'Benefit' must include benefits to quality of life.

An approach using Quality-Adjusted Life Years (QALYs) has been used by numerous governments to set funding priorities.<sup>ii</sup> Roughly, QALYs promise a formula that will yield better answers about the likely benefit of various treatments. Suppose that on average a proposed treatment is expected to add 1 more year of life to its recipients, and also deliver perfect health. Then that intervention yields a QALY of 1. Conversely, if the intervention adds 1 year of life, but with only half of perfect health, then it yields a lower QALY of 0.5. In other words, the expected utility of the treatment is reduced not only by a lower quantity of life but also by lower

quality of life. The most beneficial treatments, and those which we should prioritise, are those which will deliver the highest QALYs.

Despite the complexity of measuring QALYs across a vast range of diseases and treatments, their use remains central to health economics, and they are used by health care institutions and governments all over the world in making resource allocation decisions. The ethical issues are also daunting. It has been argued that using QALYs will necessarily give low priority to interventions which extend the lives of older people or people with terminal illness, which some people regard as discrimination. In normal conditions, wealthy countries may not face stark 'either-or' choices, as they usually have sufficient resources to fund a very wide range of treatments of benefit to all age groups. At this point in time however, we are far from 'normal conditions' and triage decisions are being faced by health care providers in many parts of the world.

### **Quality of life**

The ethical issues go beyond prioritising treatments for those who will likely live the longest. When the best possible treatments are not available for all, it is common for health care professionals to present their options as pure clinical decisions. The effect is to obscure the role that quality of life assessments inevitably play in any triage decision-making. Complicating matters enormously, there is little consensus on what factors raise or lower quality of life. The view that chronic and serious pain reduces quality of life is fairly uncontroversial; beyond that consensus quickly disappears. Loss of any kind of functioning and independence typically yields lower QALYs on most measurements. This is explicitly so in the NICE guidelines (UK) on access to critical care, which is heavily reliant on assessment of a patient's 'frailty', which includes an assessment of dementia.<sup>iii</sup> While such measurements could constitute discrimination against people with disabilities, the guidelines explicitly state they are not to be used for younger people and people with long-term, stable disabilities. While this may be good news, it raises the obvious question as to why 'frailty' assessments are used for older people? This cannot be a simple quantitative assumption that older people have little time left to live irrespective of treatment. Many older people, including people with dementia, live for many years with significant frailties: frailty is itself neither a gauge of quality of life nor a reliable predictor of length of life remaining after intervention.

This is not in itself a criticism of the NICE guidelines. It is to recognise that quality of life assessments is inevitable. There is an unavoidable subjective element in determining how much a factor reduces quality of life, if at all. Because of this, and because stigma and discrimination against older people, people with dementia and people with disabilities is widespread, it is unsurprising that advocacy groups are

wary about triage decisions, especially when they are presented as pure 'evidence-based' clinical decisions.

## **The options**

Despite this litany of serious questions, it is unlikely we can completely dispense with judgements about how to best to allocate resources to derive maximum benefit. Yet this is what some people have proposed in the context of COVID-19. In the face of a scarcity of ventilators, there are those who argue we should adopt a 'first come first served' approach. This proposal seems to rest upon a comforting belief that we can avoid making ethically murky decisions about how to use limited resources most effectively. This is fictitious. To refuse to make a decision is also to make a decision, and one that demands justification. In such a scenario the decision to offer a ventilator to a 95-year-old over a 15-year-old because the older patient arrived at the hospital first still needs to be justified. The first come first served approach will also favour the wealthy and the well-connected, who will deploy their greater resources to make sure they get in the door earlier. It is likely to discriminate on the basis of geography, favouring those who live close to hospitals in the cities.

These are roughly the two options: to try to make judgements about how to derive maximum benefit from limited resources, or to give up on such judgements all together. The first approach is ethically controversial, and vulnerable to being distorted by stigma and discrimination regarding older age and disability. The second approach is barely defensible on any criteria.

Yet despite the threat of stigma and discrimination, there are compelling reasons as to why older people have much to gain from keeping the importance of quality of life firmly in focus. Many older people have experienced highly intrusive and undesirable interventions that have questionable benefit and have left both them and their families in considerable distress. This can be compounded for people with dementia who may not understand the disruption to their lives, and may find themselves agitated and fearful when intrusive medical approaches are adopted. In other words, many patients can be just as vulnerable to ill-treatment when complex quality of life assessments are ignored as when they are explicitly adopted.

COVID-19 highlights the range of contexts where quality of life assessments might need to be made. For example, they also arise in lock-down scenarios. If the evidence continues to support the conclusion that younger people are no more affected by COVID-19 than seasonal flu, then a full and indefinite lock down becomes profoundly problematic from an ethical point of view. In such a scenario, younger people are being asked to bear multi-generational and extraordinary costs (health, economic, educational, social, cultural) largely for the benefit of people over the age of 60-70. It seems likely that at some stage the younger will be let out of

lock-down with only the older, and with those with various health conditions, encouraged to stay isolated.

Here, too, there is much to be lost by refusing to take quality of life considerations into account. There has been considerable attention to the way in which risk-avoidance in aged care settings has been used to justify overriding residents' most basic choices about how to fill their days with meaning and pleasure. Under COVID-19, many aged-care facilities in Australia have banned all visitors or confined residents to their rooms, despite government recommendation only to limit such visits. The impact on the quality of life of many residents had been profoundly detrimental.

### **Transparency in decision-making**

If these ethically complex issues are unavoidable, the solution is to bring such complexity out into the open, whether it concerns the distribution of health resources or decisions about lock-down measures.

One way to bring that complexity into the open is to acknowledge the role of contentious quality of life assumptions buried in guidelines otherwise dressed up as based on pure 'clinical' decisions. Individuals should also have clear pathways to express quality of life perspectives, especially as it concerns their own lives. While existing guidelines such as those of NICE highlight patient input as a crucial element of good clinical practice, we deserve more discussion as to how this will work in an emergency triage context which COVID-19 might foist on us. This need for consultation is no less crucial for residents in aged care facilities, who are at heightened risk of paternalism and even infantilisation. Given the existence of widespread stigma around older age, dementia, and disability, we need assurance about the concrete measures that will be adopted in emergency 'bedside' decision-making to limit their inadvertent influence.

Yet there are many factors that threaten openness and transparency. Many doctors feel deeply uncomfortable with having to admit they are making quality of life decisions, preferring to dress them up as strictly clinical decisions. Medical professionals in Spain and Italy attempted to deny they had guidelines to favour younger patients in the allocation of ventilators, presumably fearing a public backlash and erosion of trust. Politicians are even more wary of transparency. Many governments have refused to release the modelling they have relied on to make lock-down decisions, also fearing a backlash as well as the unchecked dissemination of ill-informed opinion. Many ordinary citizens also play our part in being unwilling to confront the sometimes awful choices that confront us.

The solution is not to deny that quality of life considerations play a role in triage and allocation. Nor is the solution to turn a blind eye to the reality of stigma against older people and people with dementia and other disabilities. The only ethical way forward is full openness and wide community discussion about the ethical complexities we must confront.

### **Next steps:**

A pandemic is not the best time to seek reflections on the ethics of medical resource allocation decisions. But it is an opportunity for Alzheimer's organisations and ADI to put a spotlight on discrimination against people with dementia in access to medical care and to assist people short term and in the longer term to set the scene for a more informed debate on the issues that need to be addressed. These issues go beyond ethics to societal and cultural values and structural issues.

The context for considered discussion is not encouraging. There is a collective failure to discuss end of life issues and health resource allocation. The need is not just for high sounding principles and protocols valuable though they are, but action that goes to changing health policies, medical decision making and ageist thinking.

Possibly four priorities need to be addressed by advocacy organisations that go beyond the interests they have in a disease. These are to:

1. Advocate for open discussions about the allocation of health resources at the national and international levels. <sup>iv v</sup>
2. Seek equal involvement of consumer organisations and the broader public with medical professionals in the agreement of protocols around medical decision making. This will require far greater transparency on such issues than has been the case to date.
3. Actively pursue the adoption of approaches to patient centred care that promote partnership between the medical professionals and their patients and better inform patients on decisions that impact on the length and quality of their lives. <sup>vi vii</sup>
4. Advocate for legal structures that assist consumers to express their end of life wishes in respect of treatment and to protect their rights<sup>viii</sup>.

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<sup>i</sup> <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>

<sup>ii</sup> [https://en.wikipedia.org/wiki/Quality-adjusted\\_life\\_year](https://en.wikipedia.org/wiki/Quality-adjusted_life_year)

<sup>iii</sup> <https://www.nice.org.uk/guidance/ng159/chapter/2-Admission-to-critical-care>

<sup>iv</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1376429/pdf/jmedeth00291-0009.pdf>

<sup>v</sup> <https://plato.stanford.edu/archives/win2016/entries/publichealth-ethics/>

<sup>vi</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1119673/>

<sup>vii</sup> <https://www.betterhealth.vic.gov.au/health/ServicesAndSupport/patient-centred-care-explained?viewAsPdf=true>

<sup>viii</sup> [https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2005\\_057.pdf](https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2005_057.pdf)