Allocating Scarce Resources to People with Dementia During a Pandemic

The global pandemic of COVID-19 caused by Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) is putting unprecedented strain on healthcare systems. Even in high-income countries there are regional shortages of critical resources including mechanical ventilators.[1] Because the prevalence of dementia rises with age, people with dementia are expected to bear a disproportionate burden of this severe illness compared to those of younger age.

Here, we provide principles for considering dementia as a criterion for access to lifesaving care, including mechanical ventilation.

The principles were generated by a task force commissioned by the Alzheimer Society of Canada that included experts in neurology, geriatrics, psychiatry, intensive care, ethics, and knowledge translation.

Dementia as a heterogeneous syndrome with long disease duration

Dementia is a heterogeneous clinical syndrome with multiple causes and a variable trajectory[2]. It is defined as an acquired decline in social and occupational functioning due to impairments in cognition[3].

The diseases that most commonly cause dementia are Alzheimer's disease, vascular disease, and Lewy body dementia, often in combination. Alzheimer's, the most common cause, has no disease-modifying treatments and is progressive but can have a long disease duration (average 7-10 years[4]). Some causes of dementia, such as vascular disease, may be treatable and thus not all those with dementia experience progression.

Discriminating different causes of dementia is challenging using current diagnostic testing; therefore, caution should be exercised when making individual prognoses.

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The term "dementia" encompasses a wide range of severity:

- **In its earliest stages**, there are difficulties with more complex daily activities such as managing finances, shopping, household tasks (e.g. cooking), and driving.
- **In the moderate stages** there are difficulties with basic daily activities like dressing and bathing.
- **In the more severe stages**, the person with dementia is dependent on others for daily activities.

In Canada, most people with dementia (61%) live in the community[5].

Decisions on lifesaving resource allocation based on individual characteristics

Dementia affects older people and increases their risk of dying. It is important to integrate these facts into resource allocation planning. However, given the variation in causes and trajectories of the conditions that cause dementia, the diagnosis *per se* does not reflect the wide range of function and physiological reserve experienced by people with dementia.

To assist with resource planning, we suggest that the following principles should be considered when planning access to scarce resources:

1. Decisions on access to lifesaving resources for people with dementia should be individualized.

Dementia is a heterogeneous syndrome with a wide range of severity and variation in individual trajectories. People with dementia live many years with good quality, given the average of 7-10 years of disease duration. Thus, decisions to provide or withhold lifesaving care for people with dementia should be based on individual characteristics. Blanket restrictions on lifesaving care for people with dementia are not appropriate. People with dementia should be treated similarly, using the same frameworks, as those with other serious conditions such as heart failure and metastatic cancer.

2. People with dementia should be provided the opportunity to indicate their wishes regarding goals of care.

People with dementia should have the opportunity to express their wishes, including whether they wish to be resuscitated in the event of severe illness. This process is critical to support the ethical principle of autonomy and ideally should be carried out in advance of serious illness.

3. Decisions on resource allocation should respect the personhood of people with dementia.

In an emerging pandemic where healthcare needs exceed available resources, protocols to triage access to resources are required. In response to this challenge and to address the unfortunate history of stigma against people with dementia within the healthcare system, it is strongly encouraged to meaningfully engage with people with lived experience and their care partners in developing these protocols. The rapidly evolving circumstances may only allow limited engagement at first, but it should be expanded over time. Resource allocation protocols should similarly treat people with dementia as those with other health conditions, without discrimination. To reduce stigma and promote equity, it is preferable to define guiding principles in advance. The use of a triage committee could relieve individual clinicians of the burden of making life or death decisions and promote fair, equitable access.

4. Decisions on access to lifesaving resources should be based on expected survival, not presumptions about individual quality of life.

Many people with dementia report good quality of life that is sometimes underestimated by those around them, even their own care partners[6]. Clinicians and healthcare administrators should not assume that dementia is synonymous with intolerable suffering. Emanuel and colleagues offer the perspective that maximizing survival should be the primary objective in a pandemic situation, instead of attempting to predict the future quality of life with limited time and information[7].

5. Prognostications should be based on an objective, validated assessment of mortality risk, frailty, or functional disease stage.

When guidance principles for access to lifesaving resources are based on expected survival, they should be informed by the best available evidence. Assessment should be based on a validated scale that is quick, reliable, and can be implemented and understood by clinicians who are not dementia specialists. This reduces the heterogeneity and risk for bias that could creep into individual clinician judgments. Advancing dementia causes frailty, which can be measured using a simple global index such as the Clinical Frailty Scale (CFS)[8] which has been made available freely online[9]. CFS scores correlate well with future mortality[8]. Although not commonly used in clinical practice and not intended for the purpose of determining access to care, there are mortality risk models that have been developed for people with dementia[10]. Another reasonable alternative is to base decisions on dementia functional stage[11].

6. The presence of Mild Cognitive Impairment (MCI) should not be used as a criterion for assessing suitability for lifesaving care.

MCI, also called minor neurocognitive disorder, is a risk factor for developing dementia although many people with MCI remain stable or improve over time[12]. People with MCI do not have disabilities and are able to live independently despite objective evidence of lower performance on cognitive testing.

7. People with dementia who are denied potentially lifesaving care are entitled to an explanation and best alternative care, including palliative care if appropriate.

If the number of individuals with severe COVID-19 exceeds the capacity of mechanical ventilators in Canada, ventilatory support will likely be denied to some people with dementia. To respect their personhood and preserve trust in the healthcare system, people with dementia and their care partners deserve a frank explanation for the reason that care is being limited even though this conversation may be emotionally difficult for the care team[7]. When care is limited, people with dementia deserve the best alternative care, including access to quality palliative care as appropriate[13].

These seven principles are intended to improve care for people with dementia around the world. We hope this opinion piece commissioned by the Alzheimer Society of Canada and endorsed by a nationally representative multidisciplinary task force will prove useful for dementia care everywhere.

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