PSYCHOGERIATRICS
The Official Journal of the Japanese Psychogeriatric Society

doi:10.1111/psyg.12773 *PSYCHOGERIATRICS* 2022; **22**: 132–136

REVIEW ARTICLE

Dementia in the era of COVID-19. Some considerations and ethical issues

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Disclosure: The authors declare there are no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

All co-authors have contributed significantly and confirm their agreement to publishing this submission.

Received 6 February 2021; revision received 1 September 2021; accepted 18 September 2021.

Key words: *Covid-19, dementia, intensive care unit.*

Abstract

Living with dementia at any time brings everyday challenges for the patient and those around him/her. The Covid-19 pandemic is making daily life harder. We aim to describe the problems of people with dementia during the time of such a pandemic and address the issue of their access to intensive care units. A systematic literature search (Cochrane Library (advanced search), and PubMed) was performed (for items up to 19 August 2020) using the following terms: 'COVID-19', 'dementia', and 'intensive care unit'. Studies were independently evaluated and selected for potential analysis. Five of 35 articles initially selected met the inclusion criteria. An additional Google Scholar search identified some striking statements from relevant authorities or scientists about the difficulty of living with dementia in the era of COVID-19, and were also reported. To summarize, dementia-related behaviours, increased age, and comorbid health conditions may increase the risk of contracting the virus. People with dementia in their own homes may already feel isolated, and additional rules for self-isolation may make this worse. As COVID-19 is spreading worldwide, governments and health authorities should devise better criteria for accessing intensive care units and allocating ventilators. If someone is given preference for medical care, it should be because that person has a better short-term prognosis, not simply because that person is younger than someone else.

INTRODUCTION

In late December 2019, a novel pneumonia named Coronavirus Disease 2019 (COVID-19), caused by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2),emerged in Wuhan, China, and was soon spreading all over the world.[1] Person-to-person transmission of COVID-19 led to the isolation of patients that were subsequently administered a variety of treatments. In light of the current pandemic, governments across the world have been taking measures to protect the health, well-being, and lives of millions of inhabitants. Even religious leaders have been adhering to government plans, in order to contain the spread of COVID-19, through the decision of many churches to suspend public religious practices and move liturgical celebrations online.

Containment measures against dissemination of the viral infection have been taken for collective events such as cultural or sports gatherings and so on.

Comorbidities—which make an older adult more vulnerable to the coronavirus—are frequent age-associated chronic conditions present in many community-dwelling older adults and probably in the majority of institutionalized patients. Not unexpectedly, the population segments having the highest mortality from COVID-19 have been older adults and individuals with weakened immune systems.[2] On 20 March 2020, the COVID-19 Surveillance Group of the Italian Higher Institute of Health reported data about the characteristics of coronavirus patients who had died in Italy. Dementia was assessed as one of the most common comorbidities (11.9%) among COVID-19-positive deceased patients.[3]

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The purpose of this article is to make some considerations regarding dementia in the current coronavirus pandemic era.

METHODS

A systematic literature search (Cochrane Library (advanced search) and PubMed) was performed (with only an upper time limit, of 19 August 2020) using the following terms: 'COVID-19', 'dementia special care unit', and 'intensive care unit'. A total of 35 articles were found. The systematic literature search yielded 22 articles found by Cochrane Library (advanced search) and 13 articles found by PubMed, some of them specifically including the above-mentioned search terms in the titles, as follows: 7 articles including the word 'Covid-19', 4 including 'dementia', and 2 including 'intensive care unit'. Then, we manually searched for other relevant articles by checking the reference lists of each searched article and found an additional 4 studies, for a total of 39 articles. The studies were selected if the focus met the following criteria: (i) patients with dementia; (ii) COVID-19 as the main medical condition; (iii) intensive units as the care settings. Exclusion criteria encompassed the following: (i) studies recruiting individuals with neurological diseases different from dementia; (ii) studies recruiting patients suffering from psychiatric diseases; (iii) manuscripts written in languages other than English. One article among the 39 records was a duplicate and 33 articles were not eligible. Finally, 5 articles[4–8] were identified which met the inclusion criteria. Two authors (M.F. and D.M.C.) independently evaluated these studies according to the topic of investigation. The first author (G.C.) supervised the selected of articles and reported some additional materials consisting of statements by relevant authorities or scientists regarding the difficulty of living with dementia in the era of COVID-19. A flow chart describing the selection process is shown in Figure 1.

RESULTS

The problems of people with dementia living in such an era as the COVID-19 pandemic are discussed with respect to the following two ethical questions.

What strategies are available to mitigate the outcome of the pandemic among patients with dementia?

The COVID-19 pandemic raises particular challenges for patients with dementia. Restrictions to contain the viral infection have forced people around the world to self-quarantine in their homes and to maintain social distance. However, dementia-related behaviours, older age, and common health conditions that accompany dementia can increase the risk.[4] A recent review concluded that 8% of hospitalized patients diagnosed and treated for COVID-19 had a pre-existing neurological illness.[5] Moreover, dementia represents an established risk factor for COVID-19 susceptibility.[6] Cognitive impairment hampers self-protection because a vulnerable person may not understand the risks of the disease or remember to be as careful as necessary. This makes a person with dementia an easier target for coronavirus infection. Patients with dementia may have difficulty in reporting symptoms properly or may refuse therapy due to lack of insight. They might not cope sufficiently with safeguarding measures, such as wearing masks and washing their hands, which could expose them to a higher chance of infection. They are likely to have difficulty remembering social distancing recommendations as well. People with dementia living alone may be especially vulnerable. In light of government advice in some countries about staying at home and the need to shield care home populations, it is recommended that care homes not allow visiting. In this scenario, people affected by dementia as well as their relatives are especially vulnerable and suffer from these limitations more than other people. Older adults, especially in conditions of isolation and those experiencing cognitive decline, may become more anxious, angry, stressed, or agitated during the outbreak or while in quarantine.[7] The restrictions pose particular challenges for patients who exhibit 'wandering' behaviour but nevertheless require isolation.[8] Now, more than ever, people with dementia and their caregivers need help and support from family, friends, and the facility staff who deal with them. In particular, care home staff are encouraged to work with residents to address their fears and vulnerabilities regarding COVID-19, especially while they are unable to have visitors. Moreover, older

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adults living in nursing homes have lost a great part of their social activities. Furthermore, group activities in nursing homes have also been prohibited. Confined to their rooms or apartments, these adults remain without social contact. Technology offers several ways for isolated people to still stay connected with the outside world.[9] Preparing a tablet and providing it with contact information for family members and friends, photos, social media sites, and games is a great way to help patients keep connected with their relatives, even though we should not forget that physical contact is very important and can only partially be replaced by electronic communication. However, people with dementia show cognitive limitations and may have difficulties in absorbing and being able to incorporate new technologies.[10]

It is necessary to implement active screening of residents and essential and non-essential healthcare personnel for fever and respiratory symptoms. Caregivers must monitor family members closely and respond quickly to any signs of distress, discomfort, or increased confusion. These signs do not necessarily indicate a serious condition such as COVID-19, but caregivers must be diligent in investigating what is causing any sudden or sustained change in behaviour.

What makes one life more worth saving than another?

It is a human obligation to care for patients. Sir Patrick Vallance, chief scientific adviser for the government of the United Kingdom, explained on 18 March 2020 that 'the various COVID-19 measures aim to ensure that the National Health Service's intensive care capacity is not breached'.[11] Moreover, it was affirmed 'that tragic decisions about who lives or dies will be necessary'.[11] Which patients, whether those suffering from COVID-19 or other life-threatening conditions, should get priority? In a patient-centred approach, we try to adapt the treatment to the best possible way for ensuring the well-being of the patient and satisfy his/her wishes. A thought that is emerging, however, is the following: a crucial element of situations involving a large number of sick people that we can no longer care for adequately is that we have to switch from a patient-centred approach to a group- or population-oriented approach.[12] Guidelines such as those provided by the Italian College of Anaesthesia, Analgesia, Resuscitation and Intensive Care Reccomendations[13] advise doctors how to deploy scarce resources when the need for them is outstripped by the demand of critically ill patients. A patient's chances of improvement are determined by the prognosis—not by the intellectual capacity,

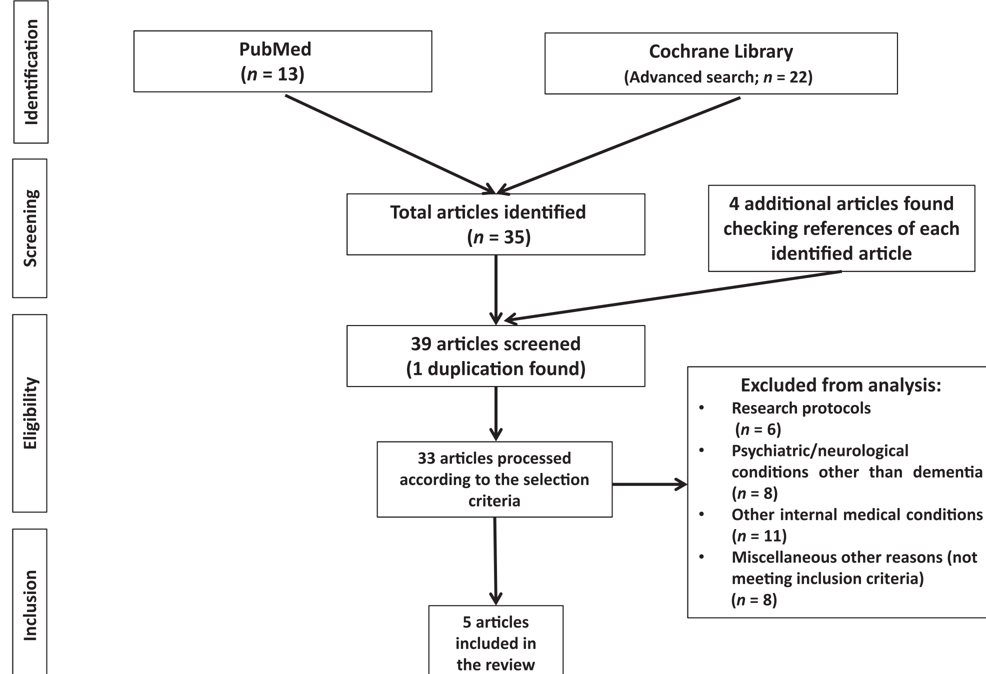

Figure 1 Flow chart showing the selection criteria and review process.

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ethnicity, or other factors. 'We don't consider anything that's not of direct prognostic value',[14] stated Mark Tonelli—a critical care physician and bioethics expert at the University of Washington Medical Centre. As U.S. bioethicist Art Caplan stated, 'people would protest the idea that young lives are worth more inherently than older lives'.[15] Physicians are in a position of institutional power, but that does not mean they are or should be the only people at the decision-making table. Difficult moral decisions should be made by multidisciplinary perspectives and teams.[16] Moreover, 'People with disabilities deserve to have equal access to scarce medical resources', wrote the American Association of People With Disabilities in a letter to Congress, 'and should not be subject to resource allocation discrimination when needs exceed supply (...) we believe that during this difficult period it is especially important to protect patients with disabilities from discrimination'.[17] As stated by Klitzman physicians need to consider patients' rights, short- and long-term risks, benefits to individual patients and society as a whole, and social justice.[18] Still, these principles can conflict and be hard to weigh. In our opinion, dementia patients have the same right to live and not to suffer. The solution to this dilemma is to improve medical resources and offer help to low-income countries. We believe it is acceptable to say that patients who have no chance of survival must receive psychological support and palliative care. However, according to the views of specialists already published since the start of the pandemic,[19,20] hospital access for people with chronic neurodegenerative conditions such as dementia, more at risk of serious consequences from the infection, cannot be postponed.

DISCUSSION

COVID-19 is disrupting life for people of all ages, but its impact has been most felt by older adults. The whole world is facing a humanitarian emergency. This crisis will shape a new culture of emergency ethics. COVID-19 and the consequent strategies to flatten the curve of its spread have created a new frontier in the treatment of dementia. This reality affects these individuals across all settings, including home, adult day services, residential and assisted living facilities, and nursing homes. The coronavirus has brought about a rise in isolation, loneliness, boredom, and fear for those experiencing dementia and for family carers. Under a range of scenarios, in different countries and regional groups worldwide, most of those who have died were older adults with health problems.[21] Equality does not mean that everyone is treated identically. However, this is very different from making clinical decisions about which individuals should live or die. Health professionals have a duty to provide care to the individual patient, but they should not simultaneously be asked to make resource allocation decisions that are intended to benefit the group rather than an individual. Now is the time to be thinking about what we can be doing to help each other.

Discrimination based on personal characteristics or situation (such as age, sex, gender identity, social or ethnic affiliation, disability, socioeconomic status, or place of residence), and the ranking of lives based on value judgements or assumptions about the quality of life, are unacceptable. Virus fatalities have until now been largely confined to older people and those with pre-existing health conditions.[21] Yet, we must maintain a keen sense that every death from this virus is deeply regrettable, regardless of whether it is a young, healthy person or someone who is old or previously ill. We need to protect our older people and people with chronic disease such as dementia from the coronavirus.

Nursing homes and other long-term care facilities can take steps to assess and improve their preparedness for responding to COVID-19. Both social distancing and self-isolation are likely to have an additional impact on people with dementia. According to Stall and Sinha, we need to think critically about the outcomes of this issue: '*When this pandemic ends and humanity survives, how will older adults view the rest of us*?'[22]

ACKNOWLEDGMENT

The authors received no financial support for the research, authorship, and/or publication of this article.

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