

Chapter 21

Impact of a world pandemic on the diagnosis of dementia

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Key points

- The COVID-19 pandemic has delayed access to diagnostic assessments and follow-up health and social care services.
- Social isolation has worsened dementia-related symptoms even in the absence of COVID-19.
- There is expected to be an underreporting of COVID-19-associated deaths in people with dementia.



General background

The global health crisis that is the COVID-19 pandemic will likely have lasting economic, logistical and health-care system consequences. Whilst attention has been rightfully focused on combatting this infectious disease, such dedicated efforts have greatly strained healthcare resources. One of the outcomes of this worldwide crisis is that individuals and their families have had to wait to obtain dementia diagnostic assessments, thus many remain undiagnosed. At the time of writing, it is too early to fully appreciate the full extent of COVID-19-related deaths

in people with dementia, but in some western countries, like Canada, the majority of deaths in long-term care facilities during this period were in fact people with dementia. The expert essays within this Chapter address the human repercussions of the pandemic on people with dementia and their families; the epidemiologic impact in Italy where the virus struck early and hard, and its adverse correlation to dementia treatment and services; and lastly, a first look at the pathological impact of COVID-19 on the brain of people with dementia.

Survey results

Among the 1,111 multidisciplinary clinicians who responded to this survey, 94% indicated that pre-pandemic waiting times for an initial assessment for suspected dementia was less than six months. However, 90% responded that additional delays had been incurred due to pandemic-related restrictions. Fortunately, 23% had no interruption in diagnostic services while 70% had partial and only 7% experienced a total interruption.

Among the 2,327 people with dementia and carers who replied to the survey, 812 had in-person access to a clinician when they presented symptoms as well as a multitude of options available via remote access (Chart 1). Notably, 163 of the respondents indicated that they were not provided any options for communication with a clinician. Among those with an in-person or virtual appointment, 72% of respondents attended, suggesting that over a quarter did not.

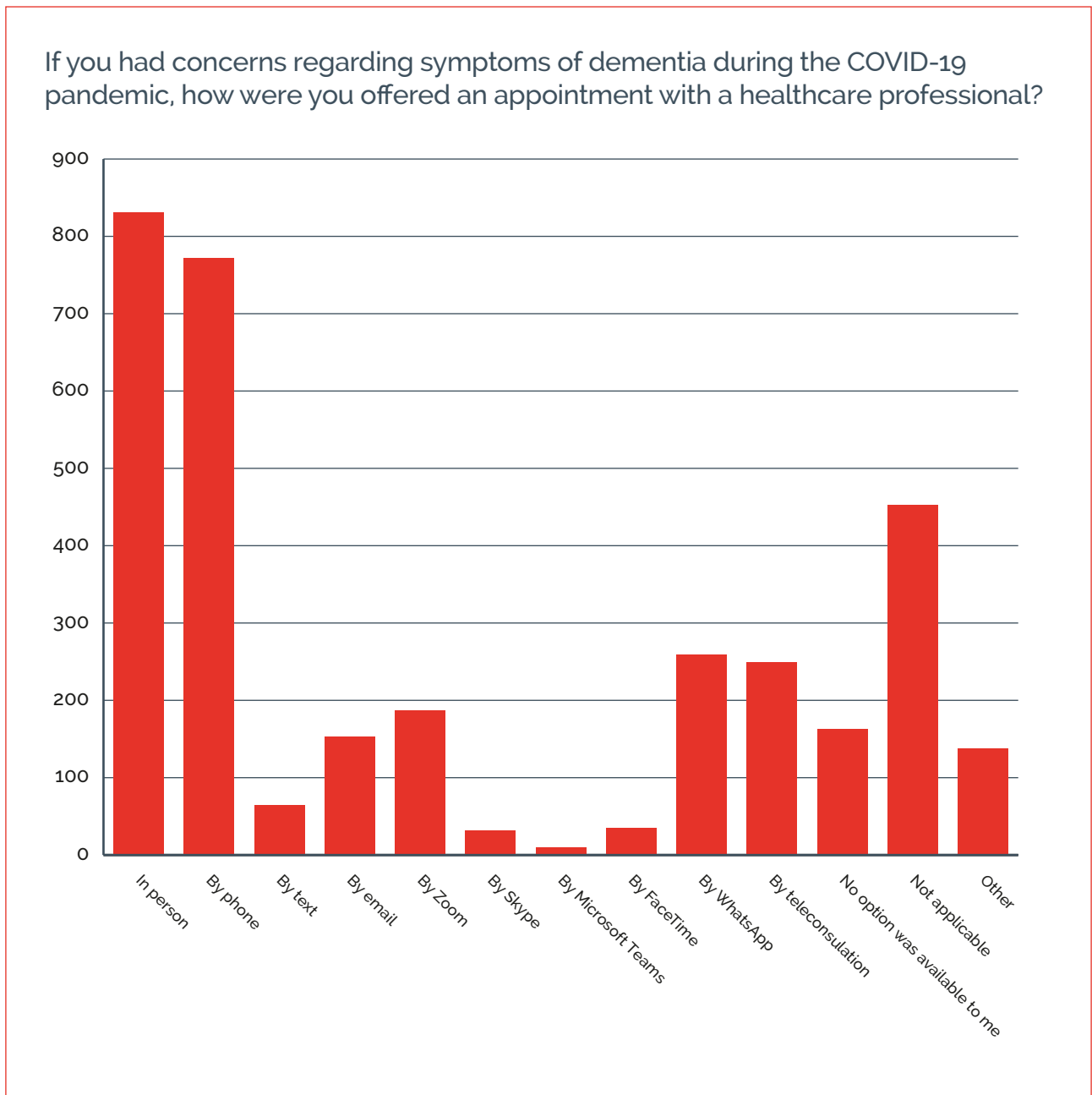


Chart 1. People with dementia and carer responses.

Expert essay

Understanding the impact of COVID-19 on people with dementia and their carers¹

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Introduction

There is an urgent need to understand the experiences of people living with dementia and their carers during the COVID-19 pandemic. Compared to other groups, people with dementia have an increased risk of contracting COVID-19, a higher risk of hospitalisation, and a greater risk of severe complications or mortality from COVID-19 (1). Globally, statistics show that up to 75% of COVID-19 deaths in care facilities have been people living with dementia (2). Moreover, the pandemic has significantly restricted and delayed access to dementia diagnosis and memory assessment services. In England, statistics show a steady decrease in dementia diagnosis rates, declining from 67.6% in February 2020 to 63.2% in July 2020 (3). These numbers indicate that more people are remaining undiagnosed with dementia. However, a timely diagnosis is critical as it enables people with dementia to acquire relevant information and support services, plan for the future, engage in cognitive health promotion activities, and access pharmaceutical treatments to improve their quality of life.

In response to COVID-19, several governments worldwide imposed lockdown measures and physical distancing restrictions to reduce the spread of the virus. These measures included limitations on social gatherings and travel outside of the home, visitation bans in long-term care facilities, and restricted/terminated access to healthcare services and supports. However, such constraints are having adverse effects on people with dementia and their carers. Research shows that carers of people with dementia are overwhelmed by the

additional caregiving needs that the pandemic has imposed on them. Despite this, research focusing on recognising how COVID-19 has defined the experiences and needs of people living with dementia is currently scarce. Given that, the purpose of this investigation was to examine the impact of COVID-19 on people with dementia and their carers, and thus, inform services and future COVID-19 policies.

Methods

Two methods were employed for this research including a scoping review and an analysis of Twitter data (4,5). The scoping review was conducted to synthesise peer-reviewed COVID-19 literature on people with dementia published between January 2020 and September 2020. Search terms included a combination of words such as: coronavirus, COVID-19, SARS-CoV-2, dementia and 'Alzheimer's disease.' Six databases were searched: Scopus, PubMed, CINAHL, EMBASE, Web of Science, and Google Scholar. Of the 420 initial records, 21 articles were included in the review.

For the Twitter analysis, tweets were collected using the GetOldTweets application in Python from February 15, 2020 to September 7, 2020. Search terms included keywords for dementia (namely Alzheimer's, Lewy body disease, etc.) and COVID-19 (coronavirus, etc.). From the initial 20,800 tweets, filters were used to exclude irrelevant tweets. The remaining 5,063 tweets were exported to an Excel document for analysis and divided among 7 coders with an additional coder managing inter-coder reliability during thematic analysis.

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Results

Based on the analysed research, five themes emerged: i) lockdown and confinement challenges; ii) separation and loss; iii) unpaid sacrifices of formal carers; iv) COVID-19 confusion, despair, and declining psychological health; and v) informal carer fatigue and burnout.

Lockdown and confinement challenges

A prevalent theme that emerged was the issue of COVID-19 lockdown and confinement challenges. These difficulties included changes to daily routines, physical inactivity and limited or terminated access to health services and supports. These may have included dementia diagnosis and memory assessment services, home care, day care, meal programmes, respite care, healthcare specialists, exercise programmes, cognitive therapy, and adequate long-term care housing. Loneliness and mental health struggles were also at the forefront of the shared comments. The challenges that lockdown presented are illustrated in the following tweets:

'... My mother cannot get care support as she does not currently have a dementia diagnosis because all her appointments have been cancelled since March. There have been no COVID deaths in the local hospital for weeks...'

'... the hardest part is being stuck 24/7 in the house with my mom who has severe dementia. It is hell! She had a day care but it closed. I can't get respite bc [sic] I'm terrified of exposing her to covid [sic]. I fight loneliness, depression and boredom everyday [sic]'

Separation and loss

Another major theme was the psychological sense of loss and separation resulting from the actual physical barriers imposed during the pandemic. Specific instances of separation included separation due to death, during the dying process, and those resulting from visitation bans in care facilities such as long-term residences or hospitals. Underlying these instances of physical separation is a clear psychological disconnect accompanied by feelings of loss. This is also evident when related to a heightened awareness of accelerated cognitive decline in the person with dementia during the pandemic. This theme of separation and loss is depicted in the following tweets:

'My husband passed away... victim of COVID protocol! He had dementia, didn't understand why I couldn't visit him. He lost hope, 36 lbs in 23 days; could not be saved. This is so cruel to do to our seniors/ he was a veteran!!! WRONG!!!'

'Let me tell you what this covid [sic] lockdown did, it killed my daddy. He had dementia and he was still doing good, then the lockdown, we weren't there to hold him and to help feed him. When we went to see him, he was a shell, there was nothing left of him...'

Unpaid sacrifices of formal care providers

The theme of unpaid sacrifices made by formal carers (such as long-term care facility workers, care aides, nurses, and more) was especially predominant throughout the tweets. Formal care providers identified numerous personal sacrifices made for work and to provide care during the pandemic. For instance, these formal carers described sacrificing their participation at family events, parenting responsibilities, and social activities to help protect individuals with dementia and family members from potential exposure to the virus. Carers universally expressed an emotional connection to people with dementia as well as a sense of duty in providing care, noting that this was 'more than simply a job.' In turn, many conveyed concerns for the health of their own families due to exposures at work. Limited personal protective equipment and social distancing challenges were two of the reasons for this. They also made trade-offs to help ensure the safety of the people they were caring for by limiting their outside contacts. These sacrifices are highlighted in the following tweets:

'I'm a nurse with COVID, probably from reusing dirty N95s and working with dementia patients who could not grasp the need to wear a mask and social distance.'

'I'm a mental health nurse working in a dementia specialist nursing home. My fight is to keep corona [sic] out of the building. There are many of us who will be in hiding to protect our residents...'

COVID-19 confusion, despair, and declining neuropsychological health

Another theme that surfaced was confusion about COVID-19 itself by people living with dementia. As a result, feelings of despair and declining psychological health set in. Many tweeters described how they had difficulties understanding COVID-19 as displayed or personally experienced. The negative psychological repercussions included depression, agitation, anxiety, difficulties sleeping, and cognitive decline. Tweets reported that people living with dementia often could not understand the changes imposed by the pandemic response, such as the visitation bans, social distancing, personal protective equipment, and lockdowns. They required constant education, reminders, and reassurance. The convergence of COVID-19 confusion, despair, and worsening psychological health are underscored in the following tweets:

'Hardest thing to hear is my mom trying to explain to my grandmother, who has dementia, that we can't see her because of the corona. My grandmother repeating that she is in jail. Asking where we are.'

'... Or live alone with dementia and all the trouble I have. I can't even drive myself to a doctor. I don't remember all the rules myself. I'm terrible at wearing a mask. Someone pointed out I had it inside out at the covid [sic] testing place. I'm gonna [sic] die, I hope. I'm [sic] tired of life.'

Carer fatigue and burnout

Carer fatigue and burnout was yet another major theme identified in the literature and shared tweets. Here, informal carers were faced with challenges related to increased workloads, financial difficulties, social isolation, fear of COVID-19 exposure, mental health issues, and terminated and/or limited access to healthcare services and support. In essence, lockdown measures substantially limited or cut off services such as home care, day care, respite, and other appropriate care home options. As such, many described the difficulty of dealing with household chores, social isolation, and the increased responsibilities, which frequently led to carer fatigue and feelings of mental, emotional, and physical burnout. The tweet below perfectly reveals how burnout is being confronted:

Another horrifying day. We are in isolation with my beloved 93 year old Mom. She has descended into terrifying hallucinations and extreme anger because of dementia. We can't get her into nursing care because of COVID..'

There is an imminent need for definitive government leadership and measures to back dementia initiatives during the pandemic. More specifically, governments must rethink a one-size-fits-all response to COVID-19 policy and use a collaborative approach to support people with, or seeking a diagnosis of, dementia. Lockdown policies and the ensuing lack of services have created a support vacuum and have rendered it imperative to make these resources available again. With little access to these healthcare support systems, people with dementia and their carers have now reached crisis point. Moreover, dementia diagnosis and memory assessment must be reprioritised to provide critical healthcare and information during the pandemic. In developing COVID-19 policies and programmes, there is a vital need for collaborative research and co-creation methods to ensure maximum impact.

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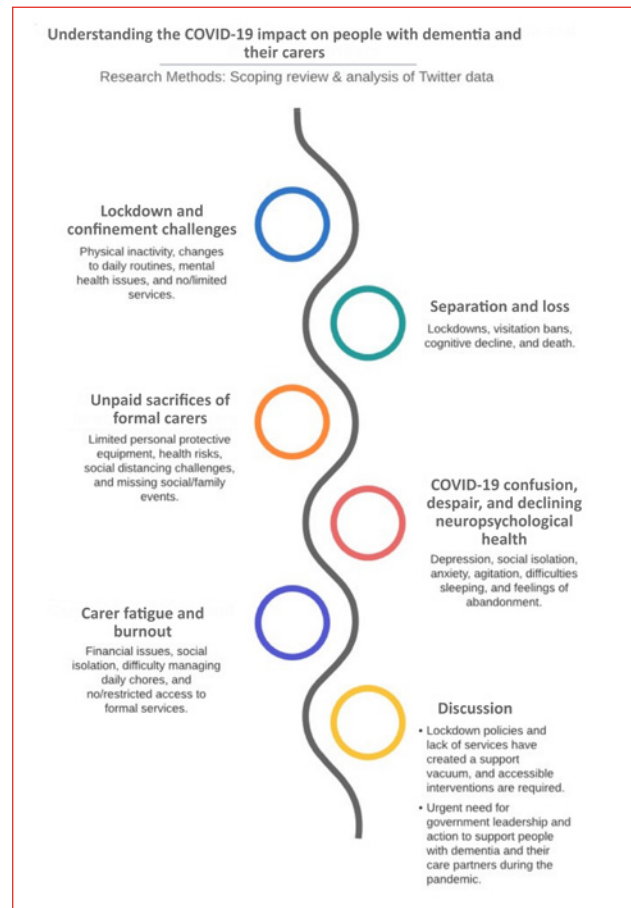


Figure 1. Scoping review and analysis of Twitter data.

Expert essay

COVID-19 and dementia in Italy: a critical appraisal

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As of June 23, 2021, a total of 4,253,460 COVID-19 cases and 127,291 COVID-19 related deaths were recorded in Italy, placing the country in eighth place among the nations hardest hit by the pandemic (1) and among those with the highest case-fatality rate.

The COVID-19 pandemic has had, and continues to have, a profound impact on the health and well-being of people with dementia living in Italy. Based on the data extrapolated from the medical reports of approximately 7,200 individuals who died with COVID-19 in national hospitals between February 2020 and April 2021, 31.8% of the women and 17.5% of the men had a history of dementia (2). Several studies conducted in the country have suggested that these high mortality rates in people with dementia may be linked to:

1. The tendency of COVID-19 to present with atypical and misleading manifestations, such as delirium and behavioural disruptions, in older adults with cognitive deficits. This often results in delayed diagnosis and treatments (3).
2. The reduced access to intensive care and supportive therapies (4).
3. The number of people residing in long-term care facilities where the transmission of SARS-CoV-2 was more protracted and where significant organisational issues and resource shortages occurred (5).

Other studies conducted in Italy have also shown that a large percentage of people with dementia who did not contract the infection experienced a considerable decline in their cognitive, functional, and behavioural disturbances (6,7). This clinical deterioration was likely the result of changes imposed by the epidemic that affected their daily routines, placed them in prolonged isolation, and interrupted dedicated services, such as day care centres.

Underreporting of people with dementia dying with COVID-19 in Italy

Excess mortality, defined as the difference between all-cause mortality in observed and expected deaths, is considered a more accurate indicator of the COVID-19 death toll. The excess includes deaths correctly attributed to COVID-19 as well as those that went unreported or were incorrectly ascribed to other causes (8).

In 2020, the total number of deaths in Italy from all causes (n=746,146) was the highest recorded since the Second World War. Overall, 100,526 more deaths were registered comparatively to the 2015–2019 average, resulting in a 15.6% excess (9). Examining the age groups, the increase in deaths among those over the age of 80 accounted for 76.3% of the overall excess mortality (9). Unfortunately, complete analysis is not yet available for the 2020 year on the specific causes of death.

According to an Italian National Institute of Statistics report based on death certificates, 49,000 excess deaths were registered from March to April 2020, compared to the average for the same months in the previous five years. Considering the initial/underlying cause of the death, 60% of the deaths were attributable to COVID-19 (n=29,210), 10% to pneumonia, and 30% to other causes (10). Deaths from dementia and Alzheimer's disease increased by 49% (n=2,736 excess deaths) relative to the reference period (10). This data suggests that many people with dementia may have died during the first wave of the pandemic with undiagnosed COVID-19 or as a result of the fragmentation of care that prevented proper management of other concomitant medical conditions. Italian excess mortality diverged when verifying the location where death occurred, namely 155% in long-term care facilities, 46% in hospitals, and 27% at home (10).

It is conceivable that these figures may even be underestimated. It is a well-established fact that dementia is frequently underreported on death certificates both as a root or contributing cause of death. In a study examining 5,311 death certificates, representing 16.7% of total deaths among people testing positive for Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) as of May 28, 2020, COVID-19 was found to be the underlying cause in 88.3% of cases. Dementia and Alzheimer's disease were reported as underlying causes in only in 38 cases, or 0.7%, and as a comorbidity in 6.1% of certificates (11). The findings show that dementia is indicated on death certificates at a significantly lower rate than data obtained from medical records. These indicate that 15.8% of COVID-19-related deaths occurred in people with dementia during this same period. (4). In the second half of 2020, the discrepancy between death certificates and clinical data widened. More precisely, dementia was reported as a comorbidity in people deceased with COVID-19 in 11.9% of cases based on death certificates as opposed to 30% of cases based on medical records (12). Therefore, it appears likely that the number of people with dementia who have died with COVID-19 is significantly underestimated.

The impact of the COVID-19 pandemic on dementia services in Italy

The pandemic also wielded a major impact on the services dedicated to the diagnosis, treatment, and care of people living with dementia and cognitive disorders.

As observed in other countries, most outpatient services (known as Centres for Cognitive Disorders and Dementia, CCDDs) markedly reduced their activities. For instance, between March 2020 and April 2020, 66.7% and 77.4% of patients respectively missed their first and follow-up appointments at a tertiary CCDD in Rome due to the government's restrictive measures (13).

Concurrently, most day care services closed, making the daily management of people with dementia even more difficult as it was almost entirely entrusted to families and formal carers.

Italian long-term care facilities faced critical situations with the SARS-CoV-2 outbreak. A national survey, covering the period of March 25 to May 5, 2020, was conducted to collect information regarding the spread and impact of the SARS-CoV-2 infection in long-term care facilities, and on how suspected and/or confirmed cases were managed within this setting (5). A total of 1,356 facilities hosting 100,806 residents were surveyed. Overall, 9,154 residents died from unrelated causes from February 1, 2020, to the questionnaire's completion date. Among them, 7.4% had COVID-19 and 33.8% had flu-like symptoms, most of whom were not provided with SARS-CoV-2 testing. Lack of personnel, difficulty in transferring people to hospitals or other services, residents isolating with COVID-19, high number of occupied beds, and specific geographic locations such as northern and central Italian regions, were positively associated with the spread of COVID-19 in these facilities (5). About one-third also reported the occurrence of adverse events, defined as any harm or injury resulting from medical care or the failure to provide care. These included falls, injuries, behavioural disorders, delirium, adverse drug events, dehydration, and bowel obstructions (14). The facilities that reported adverse events also indicated a higher use of psychoactive drugs and physical restraints compared with those that did not report any event. The determinants associated with these adverse events were the high number of occupied beds, residents hospitalised with flu-like symptoms and the geographical locations (14). The identification of these variables highlighted a pattern in facilities that were faced with critical situations at the virus' outbreak.

In October 2020, the Italian Dementia National Plan Working Group released the 'Interim guidance for the appropriate support of people with dementia in the current COVID-19 pandemic scenario'(15). This document provides practical information and recommendations on how to improve individuals' care at home and in outpatient, semi-residential, and residential settings. Its contents have already been disseminated to all Italian dementia services and general practitioners.

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Expert essay

COVID-19 and dementia incidence

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Global trends suggest that dementia incidence rates are declining in some western communities by as much as 5% despite population growth. However, in low- and middle-income countries (LMICs), these rates appear to be increasing (1). The current pandemic caused by the Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2), or COVID-19, has major global implications for dementia rates including Alzheimer's disease. Several factors are likely to change the dynamics of dementia incidence now and for years to come, with specific impact on long-term care. Older people with cognitive impairment or dementia are more susceptible to viral infection because of their age, co-existing morbidities, immunosenescence (ageing of the immune system), and reduced ability to adhere to preventive measures (2). While it may vary from country to country depending on economic status and social structure type, up to 70% of the retired older people with Alzheimer's disease or another form of dementia may reside in long-term care facilities. In some instances, throughout 2020, as many as three-quarters of SARS-CoV-2-related deaths reported occurred in care residences. (3). Once infected, older people with dementia died earlier than expected, whereas survivors succumbed to long-term consequences or long-haul COVID. This is complicated by the uncertainty and variation in cases of SARS-CoV-2 infected older people who may already be in the prodromal phase or have early cognitive impairment. COVID-19 protective measures that included confinement and isolation, restrictions on social interaction, limits on physical tasks or daily activities of living as well as a lack of emotional support normally provided by visiting staff and/or family members, all likely commingled to further deteriorate cognitive, behavioural, and physical conditions in residents of care facilities and made them more vulnerable. Incidences of family dynamics stress, under these same conditions, were also a contributing factor to weakened

resilience. In poorer economies of many LMICs, the peculiar challenges of SARS-CoV-2 for the elderly are preceded by existing fragile healthcare systems, ongoing poverty and poor healthcare financing. Infection may have further predisposed an elderly adult to worsening neuropsychiatric symptoms such as anxiety, agitation and depression (4).

SARS-CoV-2, as well as other members of the human coronavirus family, are neurotropic and act as pathogens in the central nervous system. The neurological symptoms associated with SARS-CoV-2 infection include confusion (brain fog), headache, ageusia, anosmia, dizziness, epilepsy, and acute cerebrovascular disease. Post-mortem studies confirm the presence of both SARS-CoV-2 antigen and ribonucleic acid (RNA) in the brain tissue of COVID-19 individuals, suggesting direct invasion of the virus into the central nervous system. While the virus may hasten death or dementia, it may also cause neurological injury or accelerate brain ageing mechanisms to cause new dementia variants within the spectrum of long-term complications of COVID-19 (5). This is analogous to the notion that HIV survivors on combination antiretroviral therapy (ART) may unmask dementia syndromes including Alzheimer's type of pathologies (6). Up to 30% of SARS-CoV-2 infected individuals may suffer strokes and a percentage of those who survive may develop delayed post-stroke dementia (7). Given all these factors, it is difficult to predict exactly how dementia diagnosis or prevalence will change but it is probable that dementia and Alzheimer's disease diagnosis will undergo a major change, particularly because of expected variant presentations. Meanwhile, to mitigate some of these challenges, healthcare services have continued to provide consultations and clinical care via telemedicine and even established home-based care for ambulatory geriatric patients to prevent the risk of infection by attending regular hospital visits.

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Conclusions

The impact of the COVID-19 pandemic is far-reaching, and we have yet to cross the finish line. Most countries enforced lockdown measures to contain the spread of the virus which greatly restricted people's movements and cut off much access to healthcare services for people with dementia symptoms, or follow-up appointments for those already diagnosed. Not only that, but it resulted in feelings of isolation, separation and loss with ensuing repercussions manifesting as depression, agitation, anxiety, troubled sleep, and cognitive decline. It also placed the onus of responsibility on informal carers who faced their own challenges with increased workloads, leading to carer fatigue and burnout as services that provided needed respite were closed.

As an example, the impact of COVID-19 in Italy has been extensive with high death rates. Greatly affecting the older population in long-term care facilities, many experienced additional deteriorations of cognitive and functional ability. This too can be traced to the reduction or cessation of medical and support services. The full measure of COVID-19's effect is not fully known as data from death certificates and medical records varies substantially in reporting dementia as a contributing factor.

The fact is, older people with cognitive impairment or dementia who reside in long-term care facilities are more susceptible to infection, leading to higher rates of death in this age group and setting. The isolation imposed by lockdown measures exacerbated conditions in low- and middle-income countries where fragile healthcare systems already exist. In the interim, efforts to set up telemedicine and home-based care for geriatric individuals are aimed at providing reliable medical care.