

Article

International Dementia Policies and Legacies of the Coronavirus Disease 2019 Pandemic

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Tremendous successes in public health and economic development have enabled people all over the world to live longer and, while this has many benefits, it also requires countries to adapt their health and long-term services and supports (LTSS) systems to the implications of an increasingly older population. One implication is a much larger number of people living with Alzheimer's Disease and related dementias. Worldwide it is estimated more than 57 million people are currently living with dementia, and that by 2050 that number will rise to nearly 153 million ([GBD 2019 Dementia Forecasting Collaborators, 2022](#)). This increase has been recognized as a global challenge and, in response, in 2017 the World Health Assembly adopted the Global Action Plan on Dementia (World Health Organization [[WHO](#)], 2017).

Several countries have adopted national dementia plans to coordinate efforts across different government departments and levels, along with nongovernmental stakeholders, to bring about policy change that enhances the prevention, treatment, and care of people living with dementia and their care partners ([WHO, 2017](#)). While the adoption of these plans is undoubtedly important, the implementation and resourcing of the aspirations contained within the national plans also requires major reforms to the health and LTSS systems of countries.

The importance of tackling some of these reforms has been brought to the forefront of public discourse during the coronavirus disease 2019 (COVID-19) pandemic. The multiple

impacts of the COVID-19 pandemic on people living with dementia and their care partners have exacerbated many deeply embedded inequities and challenges to dementia care around the world. People living with dementia are at a heightened risk of poor outcomes after contracting COVID-19 ([Tahira et al., 2021](#)) and account for a disproportionate share of all COVID-19 cases and deaths ([Gilstrap et al., 2022](#); [Suárez-González et al., 2020](#)). Throughout the pandemic, dementia care partners have shouldered bigger burdens due to reduced supports and increased isolation, resulting in part from curtailed access to typical sources of care and support and some unintended effects of infection avoidance practices ([Carbone et al., 2021](#); [Giebel et al., 2021](#)).

The pandemic also has diverted the attention of governments, in particular the departments and ministries that would usually be involved in developing and implementing dementia-relevant policies and programs. This reduced focus has resulted in disruptions in policy making and implementation processes and postponement or shelving of many reforms ([Alzheimer's Disease International, 2021](#)). Indeed, in an effort to refocus the important work, it is even more important to take stock and consider what should be learned from the pandemic and how these lessons can shape national dementia-relevant policies and planning efforts. We use the WHO's Global Action Plan on Dementia's seven action areas to structure the discussion of these considerations ([WHO, 2017](#)).

Dementia as a Public Health Priority and Impacts on Human Rights

Progress in the development and implementation of national dementia plans, or key reforms to support their implementation, stalled during the pandemic. In England, for example, the equivalent of the National Dementia plan covered the period of 2015 to 2020 (Department of Health and Social Care [DHSC], 2015) and, at the time of writing, has not yet been updated. Similarly, the implementation of key reforms to the LTSS financing system, initially adopted in 2015, are now announced to take place from October 2023 (DHSC, 2022).

The pandemic has also demonstrated systemic weaknesses in the mechanisms to protect the human rights of people living with dementia (and, more broadly, people living with disabilities and older people; Suárez-González et al., 2020). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) includes the rights to have equal legal capacity; express one's will and preferences; be safeguarded against undue influence and abuse; have liberty and security of the person; live independently; be shown respect for privacy; be shown respect for home, family, and relationships; and receive the highest attainable standard of health without discrimination (United Nations, n.d.). As Peisah et al. (2020) note, the human rights under the CRPD and other human rights treaties had not been adequately implemented in many LTSS settings prior to the pandemic.

Suárez-González et al. (2020) provide several specific, international examples of discrimination in access to health care based on a dementia diagnosis or residence in an LTSS facility (for an example from Italy, see Perobelli & Notarnicola, 2022). For example, prolonged restrictions on visiting have impacted the right to family life for those living in LTSS facilities, and measures have often resulted in a lack of respect for their rights to expression of will (Knapp et al., 2021). Countries should review the mechanisms in place to ensure the rights of people living with dementia and other people living with disabilities are protected, and not just during public health emergencies.

Dementia Risk Reduction Approaches

Early evidence suggests the pandemic has increased the potential risk of developing dementia. Reduced exercise and increased sedentary behaviors, less cognitive stimulation, poor mental health, and lack of monitoring of co-occurring health conditions (e.g., diabetes mellitus) that in turn increase the risk of developing dementia have all been documented during the pandemic (Organisation for Economic Cooperation and Development [OECD], 2021; Sepúlveda-Loyola et al., 2020; Stockwell et al., 2021; Suárez-González et al., 2021). The risks of dementia may also increase due to impacts of COVID-19 infection itself (Becker et al., 2021; Daroische, 2021). The need to revisit efforts to support dementia risk reduction strategies by governments, in partnership with key stakeholders, is clearer than ever.

Diagnosis, Treatment, Care, and Support

The continuum of care for people living with dementia was significantly impacted by the pandemic. Early detection of dementia has been identified as a global public health priority, as it allows for better care planning and management, along with the potential for individuals to receive disease-modifying treatments. Yet, much health-care utilization declined during the pandemic as in-person visits were canceled or avoided. There is evidence of a reduction in the dementia diagnostic rate from England (Office for Health Improvement & Disparities, 2021). Another pandemic-induced outcome was increased use of psychotropics among people living with dementia in LTSS settings in Canada and the United Kingdom (Howard et al., 2020; Stall et al., 2021). These findings speak to the pandemic's negative impacts on the mental health of people living with dementia.

There is evidence that robust care approaches were able to pivot in response to the pandemic, such as in the Care Ecosystem model, where care support workers were able to support care partners of people with dementia by adapting to providing care in new ways (Merrilees et al., 2022). Another example is the Green House model, a well-established approach to smaller group housing, which also appeared to fare better than larger facilities during the pandemic (Zimmerman et al., 2021). Innovative approaches to dementia care should be encouraged and supported by policy-makers.

Technology and Dementia

Using technology to support people living with dementia was already gaining interest prior to the pandemic to expand access to care (Astell et al., 2019; Lindauer et al., 2017). During the pandemic, technology played a major role and became a primary way to facilitate communication between people living in LTSS settings and their families, although there is strong evidence this did not work well for people with more advanced dementia (Comas-Herrera et al., 2022).

There have been examples of adaptation of therapeutic interventions for people living with dementia to virtual formats; for example, in an international pilot of virtual Cognitive Stimulation Therapy (Perkins et al., 2022) and in using technology to provide remote access to music therapy and low-impact exercise (Chirico et al., 2022). Technology can be expected to have an increasing role in dementia service provision, allowing greater independence and expanding the types of services and interventions available to people living with dementia and their care partners. Further, while the use of telehealth services to provide medical care exploded, there were also challenges with accessibility, particularly for individuals without internet or smartphone access. Public policies must adapt to this changing landscape to ensure equity in access and mitigate barriers to utilization.

Support for Dementia Care Partners

The prolonged course and intensity of dementia, coupled with the behavioral and psychological symptoms of dementia (e.g., depression, irritability, agitation, anxiety), which as many as 97% of people living with dementia experience, result in heavy care demands for care partners (Kolanowski et al., 2017; Steinberg et al., 2008). Typically, care provided by care partners is unpaid and unsupported. This is particularly acute in low- and middle-income countries, where formal care availability is often limited and family care partner burdens are high (Comas-Herrera et al., 2020; Ibáñez et al., 2021).

While care partner burdens increased during the pandemic (Muldrrew et al., 2021), the evidence suggests that policy efforts to support care partners generally received less attention than those to support health-care workers or paid care partners in congregate settings (Lorenz-Dant & Comas-Herrera, 2021). An exception is Germany, where financial support to family care partners included paid leave to provide caregiving activities (Lorenz-Dant & Comas-Herrera, 2021). The need to support care partners will continue to be a priority long after the pandemic. Policy-makers around the world should make support of care partners a top priority.

Information Systems for Dementia

Robust information systems that track dementia are limited or nonexistent in most countries but are needed to support the entire continuum of dementia care, from identifying people at risk for dementia to tracking and monitoring care provided across health systems. Systems that do exist are often insufficient. Too often, health and LTSS systems are siloed, and there is too little connection or formal information sharing between them. This is a barrier to better care and outcomes for people living with dementia. The pandemic further highlighted other problems, such as a lack of information sharing in care and in the ability of providers to respond to the public health crisis. Policy must approach these systems as part of the same continuum.

Summary and Conclusions

The COVID-19 pandemic has brought multiple, deeply embedded structural problems in the care of people living with dementia to the forefront. The difficulties in implementing public health measures to protect people from COVID-19 infection demonstrate the need to have mechanisms in place to monitor human rights of people living with dementia. Concurrently, some innovative care models and the use of technology have shown promise and will continue to offer opportunities to provide better dementia care in a post-pandemic world. To advance better dementia care and support, health-care and LTSS system-level reforms and dementia-specific policies are needed. A heightened global awareness of dementia and LTSS system issues, and an increased interest in research related to dementia care, may be positive legacies of the pandemic and can contribute to

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To ensure continued momentum for restoring levels of care that may have been lost during the pandemic, national and international policy efforts should focus on tangible ways to strengthen and sustain the dementia care continuum. Several global efforts to better support the dementia continuum are already taking place. The WHO's increased focus on dementia as a priority, along with their *Framework for Countries to Achieve an Integrated Continuum of Long-Term Care* (WHO, 2021), are prime examples of these efforts (OECD, 2021). Initiatives such as the OECD's Neuroscience-Inspired Policy Initiative, which draws on the frameworks of brain health diplomacy and brain capital (Dawson et al., 2020; Ibáñez et al., 2021; Smith et al., 2021), are opportunities for further momentum. Additionally, the International Long-Term Care Policy Network's LTCcovid.org was developed to provide rapid evidence review and policy analysis to inform LTSS systems dementia care. Other innovative global dementia initiatives and organizations predate the pandemic, including the Davos Alzheimer's Collaborative (<https://www.davosalzheimerscollaborative.org>), Alzheimer's Disease International (<https://www.alzint.org>), the Latin American Brain Health Institute (BrainLat; <https://brainlat.uai.cl>), the Global Brain Health Institute (<https://www.gbhi.org>), the International Research Network on Dementia Prevention (<https://coghealth.net.au>), the World Dementia Council (<http://www.worlddementiacouncil.org>), and Strengthening Responses to Dementia in Developing Countries (<https://stride-dementia.org>); these multinational collaborations are essential resources to support dementia policy development and implementation that appear to have stalled during the pandemic.

The multiple impacts of the COVID-19 pandemic on people living with dementia has exacerbated many deeply embedded inequities and challenges to dementia care around the world.

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Conflicts of Interest

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