

Supporting people living with dementia and their carers in low- and middle-income countries during COVID-19

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As COVID-19 spreads across the world, health and care systems face enormous challenges. While some low- and middle-income countries (LMICs) have recent experience of dealing with infectious disease outbreaks, the speed and severity of infection by COVID-19 observed across much of the world suggests that the challenges for LMICs will be enormous, especially given less well-developed health, care and social protection systems.

People with dementia have higher risks of comorbid physical diseases (such as diabetes and hypertension) and mental disorders (such as depression) than people of a similar age without dementia (1,2). These diseases are important, often fatal, risk factors for complications in people infected by COVID-19. While dementia is often considered a problem of the "rich world", in fact 60% of people with dementia live in LMICs (3).

Early research from the Strengthening Responses to Dementia in Developing Countries (STRiDE) project currently underway in Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa (with linked projects in Hong Kong and Chinese communities, New Zealand and Romania) indicate that people living with dementia experience particular difficulties accessing health care, both for dementia and related co-morbidities.

People with dementia, particularly at advanced stages, require substantial care and support. With some exceptions, in the STRiDE countries, only people without family support and financial means are able to access publicly funded long-term care, and the services available are almost always inadequate and insufficient. As a consequence, most people living with dementia can only rely on care provided by families or neighbours, except for the small number who can afford paid care. In many countries, the inequities generated by the expectation for family members to provide care are embedded in legislation. In addition, people living with dementia experience greater vulnerability because of dementia-related stigma and misunderstandings, as well as ageism (4).

None of the STRiDE countries have policies to support unpaid carers or to protect them from financial hardship as a result of having to give up paid employment to provide support. The pandemic makes long-standing gaps in care networks even more glaring and dangerous, and highlights the disproportionate impact on women, who provide three-quarters of all time spent on unpaid care and paid care responsibilities (5,6).

In most STRiDE countries, non-governmental organizations (NGOs) focused on dementia care are the only practical and in-person support available to the growing number of families living with dementia. They typically offer support groups and helplines, build caring capacity through training, and some provide day care and other respite services. However, most of these NGOs operate in urban areas with greater wealth and are only able to reach a small proportion of the population living with dementia.

The isolation and physical-distancing measures introduced in response to COVID-19 pose challenges to NGO activities at the time when support is most acutely needed. These NGOs are mostly staffed by volunteers, and coordination becomes difficult when offices are closed. In addition, ceasing face-to-face activities, such as support groups or day care, immediately reduces the support available and may increase carer burnout. Interrupting services may also threaten the financial viability of the NGOs themselves, as income from service provision is a crucial component of their funding models, and many lack business-continuity plans or financial reserves.

Many NGOs already operate (limited) phone helplines and virtual support groups, and are developing resources to support families affected by dementia through COVID-19, supported by Alzheimer's Disease International. The importance of support through remote interventions, such as counselling or self-help guidance, has been recognised (7). Some NGOs have also developed partnerships with research institutions and private sector organisations that enable access to webtools and educational materials on COVID-19. Technologies such as mobile-based applications may enable NGOs to provide information and offer emotional and other support. Maintaining contact with NGOs may also enable the mobilisation of support in case a carer becomes unable to care. However, unequal access to technology in LMICs may mean that NGOs are likely to reach only those with *existing* access.

The COVID-19 pandemic sheds light on the need for multisectoral, public-private partnerships and investments to adequately support people living with dementia, their families and carers.

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