



How can we ensure that national dementia plans support caregivers?

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All over the world the family remains the corner stone of care of people with dementia. In high income countries the vital caring role is often overlooked. In low and middle income countries the reliability and universality of the family care system is mostly over estimated. Caregiving for someone living with dementia is quite different from the other health issues, due to the duration of the disease, progressive nature of the disability and the fact that many caregivers themselves are older or living with possible diseases or disabilities and finally the lack of disease modifying treatments.

Typically the level of support increases as the disease progress, starting with support for instrumental activities of daily living and expanding to include personal care and eventually almost constant supervision. Dementia care is difficult and requires time, energy and physical exertion. As the disease progresses, family members will often provide care for many years and under high levels of stress for longer periods of time.

Caregiving and support should not be the sole responsibility of the family. It should also be the responsibility of the community, the government and society as a whole. However the role of the family caregiver is often neither supported nor properly acknowledged.

Family caregivers are more likely to develop depression, anxiety disorders and physical health issues among others, and they often have higher mortality rate compared to general population. Providing dementia care can become a full time job. Without adequate support, caregivers may be forced to quit work or cut back on work.

Out of the estimated US \$600 billion spent on global dementia care, over 40% is spent on informal care provided by family caregivers. Barriers to accessing caregiver support include negative attitudes to diagnosis and treatment, as well as a lack of appropriately trained work force and infrastructure. Not seeking help can be due to dementia being considered as part of aging or stigma, lack of public policy initiatives, lack of funds for services, research and training.

Strengthening the help provided to caregivers requires provision of information and resources, training, support and financial assistance. Caregivers need financial support in order to be able to continue the caregiving role in the long term.

Around 20 countries currently have a national or sub-national dementia plan. Many more countries are in the process of implementing them. I'm pleased to say most of these plans have a component that supports caregivers.

In addition, there are several technology based interventions including WHO I-Support, which is an information and communication technology platform for caregivers to reduce strain and psychiatric morbidities. All these measures should find an appropriate place in any future national dementia plans.