

Casting light on dementia's shadow

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Over 46 million people worldwide are estimated to be living with dementia, with the numbers projected to almost triple to 132 million by 2050. The strong link between dementia prevalence and age means that it is currently more common in OECD countries with older populations, though global population ageing means that the rest of the world is catching up. Between now and 2050, the number of dementia sufferers in high income countries is expected to rise by over 50%, but in low income countries, which have less developed health and social care systems, the number will more than triple.

Dementia is a debilitating condition that casts a shadow over the lives of the millions that it affects, including people who develop dementia, and their families and carers. It also has huge financial implications, with the worldwide cost expected to reach US\$1 trillion by 2018, which is more than the GDP of most countries.

Health systems have yet to find a way to deal effectively with dementia. There is currently no cure and despite billions being spent on research, existing treatments provide only limited symptomatic relief for a brief period.

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Many people with dementia have other long-term conditions and complex needs, so they are disproportionately affected by the failures in co-ordination that characterise many health systems.

Governments around the world are starting to put dementia at the top of their policy agendas and the last few years have seen a step change in international collaboration. In December 2013, the UK hosted the first G8 dementia summit in London. Follow-up events in Canada and Japan kept up the momentum and the first WHO Ministerial Conference on Global Action Against Dementia was held in March 2015.

The ultimate aim of this collaboration must be to find a cure. At the London summit, ministers set a target of developing a cure or disease-modifying therapy by 2025. Achieving this ambition will require a collaborative approach between governments, international organisations, research bodies, industry and the public.

One resource that may prove crucial to these efforts is the ever-increasing power of information technology, particularly big data. Massive amounts of population-based health and healthcare data (broad data) are routinely collected by health systems around the world and the ongoing development of electronic health records means that the scope of this data is increasing. If it can be combined with detailed clinical and biological data (deep data) then this can be a powerful tool to accelerate research.

However, the use of big data for research is made more difficult by the need to balance research goals with concerns about privacy and data protection, incompatible data systems and academic structures that can sometimes discourage data sharing. Overcoming these challenges will require international co-operation, and the OECD is helping to lead these efforts.

Even if these initiatives are successful, it will be years before a cure for dementia is widely available. In the meantime, health and social care systems must help people who have dementia to live better with the condition, and unfortunately, research shows that dementia care is not good enough.

The problems start with identifying people with dementia in the first place. In many countries, half or more of all people with dementia have not received a diagnosis, leaving them without the health and social care they need. Many people with dementia living in the community are old and isolated, and rarely leave their homes, while their family and friends who look after them are at risk of falling out of work or developing mental health problems. Long-term care institutions often use antipsychotic drugs to control difficult behaviour, despite this practice being widely condemned. Moreover, hospitals do not always recognise the condition or provide appropriate care, to the extent that people with dementia often come out of hospital in a worse state than when they went in.

Improving dementia awareness and care is therefore a policy priority, and the OECD is now working with countries to develop international indicators that can be used to monitor and compare the quality of dementia care and to drive improvements. These may be just the first steps down the road towards better dementia care, but if governments remain committed to international co-operation, then we can begin to cast some light on one of the biggest threats to health and well-being, particularly of older people, around the world. Claire MacDonald contributed.

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