



**Alzheimer's Disease
International**

The global voice on dementia



World Alzheimer Report 2016

Improving healthcare for people living with dementia

COVERAGE, QUALITY AND COSTS NOW AND IN THE FUTURE

SUMMARY SHEET

About the report

The World Alzheimer Report 2016 reviews research evidence on the elements of healthcare for people living with dementia and suggests how it should be improved and made more efficient.

People living with dementia have poor access to appropriate healthcare, even **in most high income country settings**, where only **around 50% of people living with dementia receive a diagnosis**. **In low and middle income countries, less than 10%** of cases are diagnosed. As populations age, due to increasing life expectancy, the number of people with dementia is increasing. We **estimate that there were 46.8 million people worldwide living with dementia in 2015** and this number **will reach 131.5 million in 2050**.

It is unlikely that the usual specialist-led approach to dementia care can expand fast enough to keep up with increases in need, and even more unlikely that healthcare coverage can be improved without rebalancing to give primary care a more prominent role.

The report reviews research evidence on the role of primary care within the healthcare system,

the effectiveness of case management, the reasons for and effects of hospitalisation, and palliative and end-of-life care, in relation to people with dementia. An assessment of the current care system and modelling of the costs and implications of task-shifted care pathways was carried out in Canada, China, Indonesia, Mexico, South Africa, South Korea and Switzerland.



Key findings

- Dementia care is over-specialised. Current specialist models of dementia care (where geriatricians, neurologists and psychiatrists provide dementia care) are unlikely to be able to scale up to provide sufficient coverage for the growing number of people affected by dementia – especially in low and middle income countries. In high income countries specialist services are already stretched by increasing demand. There is evidence that when primary care physicians take responsibility for dementia care they can attain similar outcomes to specialists.
- Task-shifting and task-sharing with primary care services will be a core strategy for improving the coverage of diagnosis and continuing care. Increasing the role of primary care services can unlock capacity within the system for diagnosis and continuing care, and may be up to 40% cheaper than specialist care in high income countries. Task-shifting is defined as delegating selected tasks to existing or new health professional cadres with either less training or narrowly tailored training. This may involve shifting tasks from higher- to lower-skilled health workers – for example, from a neurologist to a primary care physician – or creating new professional roles, so tasks can be shifted from workers with more general training to workers with specific training for a particular task – for example, from a primary care physician to a dementia case manager.
- Scaling up dementia healthcare is affordable. The annual costs of achieving 75% coverage of comprehensive dementia care in high income countries, and 50% coverage in low and middle income countries, by 2030, would amount to around 0.5% of total expenditure on public

The full report can be downloaded from the ADI website

www.alz.co.uk/worldreport2016

healthcare. Costs in high income countries would be mitigated by moving towards a more task-shifted system of care. With improved coverage, additional cost savings may come from reduced need for admission to care homes, and improvements in the efficiency with which healthcare is provided (avoiding unnecessary or burdensome interventions).

- The successful implementation of task-shifted dementia care pathways will require healthcare system reforms in many countries, in particular to ensure access to healthcare (especially in low and middle income countries where some people have inadequate public health cover or none at all). Also, the lack of a gatekeeping role for primary care in some countries may have a negative impact on the take up of task-shifted care and could lead to inefficient use of scarce specialist services.
- Training, mentoring and support by specialists are essential. Primary care services need to be mandated and resourced to provide dementia healthcare. The roles of specialists and non-specialists within the system need to be clearly defined. Specialist services will need to take on a more prominent role in training and supervising non-specialists, with explicit referral guidelines and pathways. In many low-resource countries primary healthcare would need to be strengthened to take on this role effectively.
- Dementia is often complicated by frailty and multiple physical morbidities. More must be done to help people with dementia to optimise their physical health, maintain their nutrition and hydration, and reduce their risks of falls, infection and delirium. The current lack of attention to these issues may be one of the strongest arguments for the greater involvement of primary care in the delivery of dementia care.
- People with dementia should be included in debates about the management of multiple health problems in older people. Their values and preferences for treatments may differ in important ways from people who do not have dementia, as may the outcomes that are most important to them.

- The needs of people with dementia, and their carers, change over time. Care systems must be responsive to this, maintaining regular contact, monitoring and reviewing care plans, and providing support and interventions to meet needs when they arise. Healthcare should be continuous, holistic and person-centred, treating the whole person according to their values and preferences, not as a set of separate health conditions or problems. Care should be integrated across all levels of care provision, and health and social care providers.
- Care pathways and case management are key mechanisms for integrating and coordinating care. Care pathways provide an explicit structure for planning, organising and resourcing integrated care across the course of the condition, and assessment and monitoring of care quality through process and outcome measures. Case managers coordinate care across health and social care systems, promoting efficiency, consistent with individual values and preferences.
- People with dementia are more likely to be admitted to hospital, have longer stays and are at increased risk of negative outcomes. Avoidance of unnecessary hospitalisation is a policy priority in many countries, but there is no clear evidence as to how this may be achieved. Home-based assessment and management, emergency department evaluation, and 'hospital at home' alternatives all require further evaluation. In hospital, specialist dementia nurses, dementia care units, and specialist liaison services can help to improve the quality of care, but there is little evidence that they help shorten admissions.
- There are significant gaps in research into health service and system innovations. These include: the cost-effectiveness of case management; the effectiveness of advanced care planning and palliative care approaches to end-of-life care; and interventions targeting the avoidance of hospitalisation for people with dementia. Researchers need to work more closely with policymakers and healthcare providers to ensure that interventions tested are realistic and relevant. Policymakers and providers should implement innovations in a way that permits evaluation and experiment.

The report was researched and authored by Prof Martin Prince, Ms Adelina Comas-Herrera, Prof Martin Knapp, Dr Maëlynn Guerchet and Ms Maria Karagiannidou from The Global Observatory for Ageing and Dementia Care, King's College London and the Personal Social Services Research Unit (PSSRU), London School of Economics and Political Science.

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Our vision is an improved quality of life for people with dementia and their families.

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