DEMENTIA REGISTRIES HAVE SIGNIFICANT POTENTIAL TO IMPROVE DEMENTIA RESEARCH

Registros de demência têm um potencial significativo para melhorar a pesquisa sobre a demência

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Dementia is a global epidemic and is the leading chronic disease-causing disability and dependence among older people. In 2015, the global prevalence of dementia was estimated at 46.8 million, and expected to double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050. There are roughly 9.9 million new cases of dementia annually worldwide, implying one new case every 3.2 seconds, which is 30% higher than the annual number of new cases in 2010. The global cost of dementia has also increased by 35% over 5 years to US\$ 818 billion in 2015. These costs consist of direct medical costs, direct social care costs (such as paid and professional home care, residential and nursing home care), and informal or unpaid care.¹ The Global Action Plan on the public health response to dementia 2017–2025 prioritizes research to ensure an evidence-based approach is used to manage this growing problem.² A global research prioritization exercise identified that the top six research priorities were related to prevention, identification, and reduction of dementia risk; and on delivery and quality of care for people with dementia and their caregivers.³ However, recruitment rates of people with dementia to participate in research is highly variable, depending on perceptions of risk, benefits, and exclusion criteria. For example, in five studies on drug treatment for dementia, recruitment rates varied widely from 80 to 1%.⁴

An approach to improve the recruitment of participants is by setting up dementia registries. At least 31 dementia registries are operating on an international, national, or local level between 1986 and 2016, with more than half aimed to conduct or facilitate research.⁵ People with dementia and caregivers appear motivated to join dementia research registries with altruistic motives to help others, without considering personal benefits or financial incentives.⁶ Several examples of registries are mentioned in this section to illustrate how they can be used to collect epidemiological data or data on quality of care.

The United Kingdom Dementia and Neurodegenerative Research Network (DeNDRoN) was established to link patients to high-quality studies. One component is DemReg, a register of dementia patients and their caregivers, who agreed to be approached for future research studies.⁷ Participants were recruited from primary and secondary care. Although the initial development was complex and fraught with ethical and organizational challenges, their experience shows that constructing and populating a dementia research registry is feasible. Although it is resource-intensive, they experienced high acceptance rates for recruitment with an effort from registry champions.

The Swedish Dementia Registry (SveDem) is an internet-based quality registry, covering almost all of Sweden, which offers continuous online statistics that can be compared with regional and national data. It was developed to improve the quality of diagnostic work-up, treatment and care of people with dementia in Sweden.⁸ Data from SveDem is also published annually to inform clinicians, political and administrative decision-makers about the quality of diagnosis, treatment and care of people with dementia in Sweden.

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The Dutch brain health registry was developed to recruit, screen and monitor people interested in participating in dementia research in the Netherlands.⁹ The online platform enables participants to fill an online questionnaire, which connects them to research. Focus groups and online surveys test user-friendliness, usability, content and visitor's needs to develop and optimize methods for effective recruitment, pre-screening and engagement in the study participation. A national media campaign with follow-up marketing strategies focusing on brand activation, user activation, digital and social recruiting was performed to launch the platform and raise awareness regarding the registry.

Finally, the Registry of Cognitive Pathologies in Argentina (ReDeCAr) was developed as a prospective national case register for hospitals and health centers in 2010.¹⁰ Although this initiative yielded useful results regarding the type of dementia patients in the country, the registry was eventually discontinued due to a change in the priorities of the Department of Mental Health. Thus, setting up registries requires long-term commitment to ensure sustainable maintenance and continuity of the database.

Overall, dementia registries can provide epidemiological data, support clinical best practice and facilitate research. There is a need to have global harmonization of recruitment methods and minimum data sets among registries to facilitate international comparisons. Once this occurs, there is a significant potential to contribute to dementia research outcomes, inform policy and service planning, and promote cost-effective dementia diagnosis and management.

CONFLICT OF INTERESTS

The author declares no conflict of interests.

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AUTHOR'S CONTRIBUTION

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