Undiagnosed dementia in primary care: a record linkage study

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Declared competing interests of authors: none

Published April 2020
DOI: 10.3310/hsdr08200

Plain English summary

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Health Services and Delivery Research 2020; Vol. 8: No. 20
DOI: 10.3310/hsdr08200

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Many people with dementia have not been formally diagnosed. Without a diagnosis, people with dementia may not have access to appropriate support, but, for some, being diagnosed might cause more harm than benefit. For example, medicines might not help and it is thought that diagnosis might lead people to give up work or other activities.

Not much is known about people who live with dementia without a formal diagnosis. In this study we estimate how many people live with undiagnosed dementia, how long it takes for somebody with dementia to be diagnosed, who is most likely to be diagnosed and whether, on average, being diagnosed is helpful or harmful.

We contacted the general practitioners of 449 people who had taken part in another research study between 2008 and 2013 and who were found at that time to have dementia and had consented to their medical records being used for further research.

We checked whether or not those people had a diagnosis of dementia in their medical record and when any diagnosis had been made. From this, we estimated that in 2011–13 around 43% of people living with dementia had a recorded diagnosis, an increase from 35% in 2008–11. People with more severe dementia, in particular those with worse memory, were more likely to be diagnosed. On average, people lived with dementia for 3.5 years before their diagnosis. Being diagnosed did not help people to live longer or stay out of care homes; there was not enough reliable information to estimate how aspects of life such as anxiety or social activity were affected.

This research suggests that a better awareness of non-memory symptoms of dementia is needed. Although everybody should have access to dementia diagnosis if wanted, more research is needed to understand its associated benefits or harms.
Health Services and Delivery Research

ISSN 2050-4349 (Print)
ISSN 2050-4357 (Online)

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Editorial contact: journals.library@nihr.ac.uk

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This report
The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 14/70/96. The contractual start date was in January 2016. The final report began editorial review in May 2018 and was accepted for publication in March 2019. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care.

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