

Undiagnosed dementia in primary care: a record linkage study

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Plain English summary

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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.

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