Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences

Record Status
This is a bibliographic record of an ongoing health technology assessment being undertaken by a member of INAHTA. Links to the published report and any other relevant documentation will be added when available.

Citation
Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences. Health Services and Delivery Research

Authors' objectives
Background to our research
About 700,000 people in England have dementia. Dementia causes a gradual loss of memory and other brain functions including language and decision making. People with dementia can cope well in its early stages and continue their normal life, but as dementia progresses they need more help with everyday tasks, and can lose their independence and the things they enjoy. Dementia can affect mood and lead to challenging behaviour and places a large strain on caregivers and relationships. What is the gap in knowledge that we will address? GPs in England reported 344,000 cases of dementia in 2013-2014, which provides a rough indication that about half of all people with dementia are not diagnosed. There are potential benefits and harms of receiving a dementia diagnosis. It is accepted that people with dementia should be diagnosed at the best time for them, and a lot of resources are going into trying to improve the diagnosis rate. However, beyond a rough estimate of their number we do not know enough about people with undiagnosed dementia. We don’t know whether more live alone, with family or in care homes, how severe their dementia is relative to others, what symptoms they experience, what level of disability and care needs they have. We don’t know how many have made contact with their doctor and are waiting for a diagnosis or how many have not sought help. Our project will address these questions by identifying a group of people with dementia but without a formal diagnosis and comparing them to a group who are diagnosed. What will we do? We will use data from a group of people found to have dementia as part of another ongoing study. The Medical Research Council Cognitive Function and Ageing Study 2 (CFAS II) selected 7500 people at random from urban and rural parts of England to have a dementia assessment. About 460 people were discovered to have dementia and gave us permission to look at their GP records. We will look at the GP records for this group to see, at the time when CFAS II found them to have dementia, which participants had a dementia diagnosis recorded by their GP and which did not, and if not whether the GP had noted any memory problems or a referral to a memory service. From this we will estimate how many people with dementia in England have not sought help, and how many have been in contact with their GP about their memory problems but are not diagnosed. We will describe the needs of the group with undiagnosed dementia and identify groups that are more likely to be undiagnosed. We will explore the benefits and harms of being diagnosed on health care use, mood, social participation and disability. Why is this study needed now? This is a unique opportunity to study undiagnosed dementia. We have the expertise required and our team is involved with shaping NHS policy on dementia diagnosis. We will present our findings to the general public, to healthcare professionals, policy makers and those in local and national government who are responsible for improving access to diagnostic services.

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