SPECIAL ARTICLE

Against the stream: early diagnosis of dementia, is it so desirable?

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Summary The Prime Minister's challenge on dementia called for improved dementia diagnosis rates, based on assumptions of benefit to individuals and those who care for them. Subsequent policies have led to increased target drives for clinical practice to achieve early diagnosis of dementia through intense case identification. However, the current evidence base and treatment options do not support screening for dementia, and there is little empirical evidence that such intensive case identification and early diagnosis for dementia is justified without a better understanding of the benefits, costs and potential harms to individuals and services.

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'Of course,' many would respond to the question in the title of this paper. The same response would be heard for any chronic disease. Surely it must be better to detect a serious condition as early as possible. Even to question this response could be interpreted as somehow unethical or immoral. It stands to reason that the earlier a health condition is detected, the more effective any intervention will be. Such is society's starting point, endorsed by the successes and widespread promotion of national population screening programmes such as screening for breast, cervical or colon cancer.

In the case of dementia, following this reasoning, early diagnosis would allow earlier treatment. The individual and his or her family would be able to plan more effectively for the future, for example, to access care and support and by making advanced decision plans.

To begin with, what is meant by 'early diagnosis' along the clinical pathway of dementia? There is evidence that dementia goes through an asymptomatic stage where there may be no clinical symptoms but precursor biological and neurological changes. This may progress to an early symptomatic stage, for example, with subjective memory complaints or mild cognitive impairment (MCI), before moving on to a later symptomatic stage where there is a clear effect on daily living with further progression to advanced dementia.[1,2] Dementia is a complex syndrome with a gradual evolution. In some people with dementia, however, these stages may not be consistent or clearly defined. For example, MCI has been defined as the grey area between intact cognitive functioning and clinical dementia,[3] but not everyone with MCI will progress to a full diagnosis of dementia.[4,5]

Further, there is a distinction between: population screening, that is, screening everyone at a population level, including healthy or asymptomatic individuals, with the aim of very early identification; applying a 'screening' test in a clinical setting, where a clinician detects symptoms during routine attendance; and using a 'screening' test in people who are theoretically at high risk but where there is no other concern for the clinician, the patient or family members.

This still leaves the question of what is meant by 'early'. The Oxford English Dictionary definition includes 'in good time', 'before the usual time', and 'prematurely'. Each of these definitions requires a different type of evidence. 'In good time' suggests a time that is appropriate for that individual within their context; 'before the usual time' suggests a pre-emptive or screening process without implication of benefit or harm; while 'prematurely' suggests the possibility of harm.

David Cameron's Prime Minister's challenge on dementia called for improved dementia diagnosis rates.[6] However, it is unclear whether this challenge reflected a push for diagnosis earlier along the clinical pathway or a concern that much more advanced cases of dementia, were being missed. Whatever was intended, subsequent policies and rhetoric have led to strong, target-driven pressure for clinical practice in England to achieve greater levels of 'early' diagnosis of dementia through increased case identification. This drive for increased early diagnosis assumes it is beneficial for all

people with dementia, without concern for the possibility that this might divert resources from other services.

A drive for diagnosis earlier along the pathway requires (1) screening and diagnostic methods with high sensitivity and specificity; (2) adequate support and follow-up to confirm the diagnosis; (3) the availability of effective treatment and support; and (4) the availability of sufficient services to provide diagnosis, treatment and support. There is an implicit assumption here that evidence-based intervention provides a positive change in prognosis for individuals and/or the well-being of those around them. Although this assumption is justified for the national cancer screening programmes described previously, this is not the case for dementia.

At the present time, population screening for dementia for all people aged over 65 is not recommended by the UK National Screening Committee,[7] despite regular revisiting of the evidence. The UK's Committee concluded that the current best screening test for dementia does not accurately identify those people who have dementia and those who do not. For every 100 people aged 65 tested, 18 would test positive, but only six of these would have dementia and one case would be missed.[7] A substantial proportion of those tested would therefore be 'false positives'. Crucially, in order to recommend screening, treatments need to be available that would slow or even prevent dementia. The Committee concluded that such treatments do not exist for dementia at present.

Additionally, for population screening programmes to be introduced, population-relevant evidence, usually in the form of trials conducted in relevant populations, is required. For those conditions where national screening has been introduced, the benefits to the population have been tested and estimated and there are effective treatments available.

Thus, to justify the introduction on a national basis of intense case identification, a robust and rigorous evidence base is required.[8] To date, no trial of intensive case identification for dementia has examined the likely effects, benefits and harm. The only evidence that is currently available is from those people who have been identified through existing identification approaches, with no systematic attention to any harm that might have been experienced.

Individuals identified through intense case identification and screening will have different natural histories from those identified through services. They are more likely to be wrongly diagnosed or, if accurately diagnosed, to have a benign course. In the absence of a well-designed trial, the benefits assumed from early diagnosis, such as support and service provision, are inevitably exaggerated. While assumed benefits of early diagnosis include planning support and services, reducing crises and family stabilisation, a number of adverse effects such as anxiety, depression and uncertainty about the future have been reported.[9] Excessive health anxiety can also be created by screening, particularly when findings are equivocal, leading to additional suffering and abnormal internet use (cyberchondria). There is also potential for diagnostic errors and diversion of resources and services from those clearly manifest cases of dementia where individuals and their families have sought help. Anxiety, depression and concern about the future have similarly been reported following a diagnosis of MCI.[10]

The process of diagnosis of dementia has been described as a 'collective, cumulative, contingent process'[11] that often develops over time. A diagnosis of dementia affects not just the person with dementia, but also their family members and the services around them. Reactions to a diagnosis and readiness for a diagnosis vary between individuals with dementia and their family/carers,[12] so it is important that the diagnosis of dementia is 'timely' or 'in good time' both for the person with dementia and the people around them. This concept of timely diagnosis means disclosure of the diagnosis at the 'right time for the individual with consideration of their preferences and unique circumstances'.[13]

The pathway from early identification of suspected symptoms usually involves referral to specialist secondary care assessment, often to memory clinics. The number of patients referred to memory clinics increased by 31% from 2013 to 2014,[14] and those people with dementia estimated to have received a formal diagnosis increased from 42% in 2012 to 62% in 2015.[15] However, confusion about complex referral criteria resulting from the drive for early diagnosis to memory clinics may have resulted in delaying referral, with a resulting negative effect on timely diagnosis.[15]

It has also been argued that relying solely on opportunistic diagnosis may lead to avoidable harm. For example, it is often stated that late diagnosis results in higher rate of falls of people with unrecognised dementia, or confusion after hospital admissions. Late diagnosis may leave people insufficient time to plan for the future. Diagnoses are still too often made after a crisis. However, these claims are difficult to test empirically – people who already have a diagnosis also experience these problems; it remains uncertain whether diagnosing dementia at an 'earlier' stage would have made a difference to an individual.

Research is needed to address these uncertainties, including experimental designs in the introduction of service changes. The introduction of major initiatives for vulnerable populations without evaluation is extremely costly and has an inevitable harmful effect on already overstretched services.

Currently, clinical efforts should be focused on achieving a *timely diagnosis* defined as when people with dementia and those around them are ready for and will benefit from it. Until there are effective treatments for dementia, and the benefits of early diagnosis to individuals and the effects of adequate support on individuals and services have been rigorously evaluated, the benefits, costs and potential harms of early diagnosis remain uncertain.

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