

Targeted case finding for dementia in primary care: Surrey Downs dementia diagnosis project

Sen Kallumpuram, CT Sudhir Kumar, Bilal Khan, Victoria Gavins, Aalia Khan, Steve Iliffe
Surrey and Borders Partnership NHS Trust

Abstract

Currently less than half of the estimated number of people with dementia in England receive a formal diagnosis of dementia or have contact with specialist dementia services. Case finding focused on high risk groups may be an effective way to identify the undiagnosed. This joint Surrey Downs Clinical Commissioning Group and Surrey and Borders NHS Foundation Trust quality improvement project aimed to increase the rate of dementia diagnosis across Surrey Downs using specialist link nurses (SLNs).

Thirty three GP surgeries covering the entire Surrey Downs area took part in the project. Individuals at high risk of developing dementia were identified from GP electronic disease registers, and were offered screening at their GP practices by SLNs, using a combination of mini cognitive test (Mini-Cog) and functional assessment questionnaire (FAQ). Suitable individuals who screened positive were seen by their GP and where appropriate referred to secondary care services for further evaluation.

Based on the presence of risk factors, 6657 (11.9%) people were identified from a total population of 55 845 over 65s, and 1980 (29.7%) completed the screening assessment. Three hundred and fifty eight (18.1%) individuals screened positive and were referred to their GP, who referred 205 (57.2%) of them to the memory services for further assessment. Of those referred, 164 (80%) had a comprehensive specialist assessment. Forty one (20%) declined further assessment, and their GPs were informed.

The mean age of the cohort who completed the comprehensive assessment was 82.3 years (SD=4.26), and were predominantly white and male. Fifty four (32.9%) had mild cognitive disorder (MCD), and 101 (61.6%) patients were diagnosed with dementia. The most common dementia was mixed type (43; 42.6%), followed by Alzheimer's dementia (32; 31.7%). The most common risk factor among patients with cognitive impairment (MCD or dementia) was hypertension (69; 44.5 %), followed by ischemic heart disease (64, 41.3%).

Nurse led case finding for cognitive impairment in a high risk population identifies people with dementia who are not yet formally diagnosed. The combined use of brief instruments to assess cognitive functioning and functional capabilities is helpful in identifying individuals with possible dementia.

Problem

Dementia is degenerative disorder with an increasing prevalence. 46.8 million people worldwide are living with dementia. This number will almost double every 20 years. There are over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds.(1) The Dementia UK update 2014 estimated that 850 000 people were living with dementia in the United Kingdom in 2015, and that dementia costs the country £26 billion a year, with an average cost of £32 250 per person.(2) The total number of people with dementia in the UK is forecast to increase to over 1 million by 2025, and over 2 million by 2051, although these may be over estimates.(3,4)

Currently less than half of the estimated number of people with dementia in England receive a formal diagnosis, or have contact with specialist dementia services. While there has been a slight increase nationally in the diagnosis rate, from 46% in 2011-12 to 48% in 2012-13, the diagnosis rate varies across the country, from 39% in the worst performing areas to 75% in the best.(5) Underdiagnosis may be a reflection of the complex nature of the

condition, due to its uncertain cause and pathophysiology, high variability in symptoms and signs, and the absence of validated diagnostic tests or monitoring measures.(6) A 2012 survey found that one third of people with dementia had waited longer than a year to go to their GP with their symptoms. The reasons for this are complex and may include an assumption that memory problems are normal in older age a fear of the diagnosis, a view that little can be done to help, and the perceived stigma of dementia.(7,8)

Background

Studies indicate that, overall, people living with dementia prefer to have early disclosure of the diagnosis.(9) The potential benefits of having an early diagnosis include maximizing decision making autonomy, by allowing the patient the chance to make important decisions about the future, including finances, while retaining their mental capacity. (10) Other benefits include ending uncertainty, as well as confirming suspicions. It also enables earlier access to services and timely access to information, advice, support and medical treatment. (11,12,13) Primary care is critically placed with unique opportunities to identify patients with dementia at an early

stage. Earlier or timely diagnosis aims to support patients and their families in order to improve their quality of life and to anticipate crises. It also enables longer independent or supported living in patients' homes and communities.

The absence of a simple and accurate test to diagnose dementia, a condition of the WHO population screening is a compelling reason for not using population screening strategies.⁽¹⁴⁾ The next best approach would be targeted case finding to screen individuals who are at a high risk of developing dementia. Various factors including hypertension, cardiac diseases, stroke, diabetes mellitus and Parkinson's disease have been identified as risk factors for dementia.^(15,16,17,18,19)

Improving diagnosis and care of patients with dementia has been a priority of the Department of Health and NHS England.⁽²⁰⁾ A common element of health strategies to improve the quality of care of people with dementia is that diagnosis should be "early" or "timely".⁽²¹⁾ In the Surrey Downs area, the diagnosis rate was 43% at the beginning of the study.⁽²²⁾ Surrey Downs Clinical Commissioning Group was successful in bidding for a project to increase the rate of dementia diagnosis across Surrey Downs using SLNs. This joint Surrey Downs Clinical Commissioning Group and Surrey and Borders NHS Foundation Trust quality improvement project was supported by the Prime Minister's National Dementia Challenge Fund. This project focuses on two of the three main areas of the National Dementia Strategy: increasing the rates of early diagnosis of dementia, and intervention in the community and improving awareness among primary care health professionals. The essence of this project is, the GP practice undertakes to make an offer of assessment for dementia to "at risk" patients and, where agreed with the patient, to provide that assessment.

The Surrey Downs dementia diagnosis project aimed to improve the diagnosis rate of dementia across the Surrey Downs area over an 18 month period. This project also aimed to raise awareness of the benefits of early and timely diagnosis among both primary care health professionals and the public.

Baseline measurement

Increasing diagnosis rates of dementia

Surrey Downs has a population of 55 845, with a predicted prevalence of dementia of 3630 (6.5%). However, the number of diagnosed patients at the beginning of this project (according to the Surrey & Borders Partnership Foundation NHS Trust electronic patient records) was only 1785, or 49% of the expected prevalence.

Preparatory work

To raise awareness about the project, education days were organized for GPs and primary care teams, focusing on the benefits of screening and early diagnosis of dementia. Four events were run across the Surrey Downs area, aimed at increasing public awareness and encouraging collaborative work between all healthcare providers. These events were overseen by the Dementia Local Implementation Group, represented by the clinical

commissioning group (CCG) Dementia lead, clinical psychologist, consultant psychiatrist, Local Social Services lead, Alzheimer's Society, and patient and carer representatives.

See supplementary file: ds6457.docx - "Surrey Downs Project Table"

Design

Setting and recruitment

Thirty three GP surgeries covering the entire Surrey Downs area took part in the project. The project started with searches in GP electronic disease registers in April 2013, and ended in September 2014. For the purposes of this project, "at risk" patients were identified from the GP electronic disease registers at each GP practice. Inclusion criteria were: (1) age >65 with no previous diagnosis of dementia, and (2) with any of the following specific risk factors, namely, diabetes mellitus (type 1 or type 2), hypertension (diagnosis of hypertension documented in the patient's notes), heart disease (any previous history of myocardial infarction or cardiac conditions which required ongoing management or review by healthcare professionals), Parkinson's disease, and stroke (previous history of cerebrovascular accidents: transient ischemic attack (TIA) or stroke). Individuals thus identified were sent an invitation letter offering screening for cognitive impairment. The invitation letter for voluntary screening was formulated after several consultations with GPs, practice managers, and members of the Alzheimer's Society, to ensure it was informative but not anxiety provoking.

Strategy

Three SLNs were appointed for the project. The responsibilities of their role included establishing a dynamic relationship with GP practices, attending practice meetings, updating on patients who had been screened, and documenting the discussions that had taken place regarding their care. The SLNs were qualified psychiatric nurses, and conducted screening assessments at the primary care level, and comprehensive assessments at the secondary care level, offering pre- and post-screening support. They linked the primary care and secondary care services, working in close collaboration with the GP at the primary care level, and the consultant psychiatrist at the secondary care level.

The screening instruments used by the SLNs were (1) a mini cognitive assessment (Mini-Cog), which consisted of a three word recall and clock drawing test, and (2) a functional assessment questionnaire (FAQ).^(24,24) The FAQ is an informant based measure of functional abilities. Informants provide performance ratings on ten items reflecting instrumental activities of daily living, scored from 0 to 3. A total score of 30 represents maximal dependence, and a score of 0 represents complete independence. This stage of the assessment took an average of 20 minutes.

A positive screen was defined as an abnormal Mini-Cog score (failure to recall any word, or a score of 1 or 2 on word recall, with

an abnormal clock drawing test), and a score of more than 9 in the FAQ. All participants screened positive were reviewed by their GP, who referred the participants to secondary services based on the available history and information provided by the SLNs, as appropriate. A dementia blood screen was arranged for everyone who was referred to secondary care psychiatric services for comprehensive assessment.

Comprehensive assessment was carried out in secondary care by the SLNs, which included history taking, mental status examination, and cognitive assessment using Addenbrooke's Cognitive Examination (ACE III). It has a maximum score of 100, and the cognitive domains correlate significantly with standardized neuropsychological tests used in the assessment of attention, language, verbal memory and visuospatial function.⁽²⁵⁾ A consultant psychiatrist then reviewed both assessments, and an appropriate provisional clinical diagnosis was made according to ICD-10 Classification of Mental and Behavioural Disorders (WHO).⁽²⁶⁾ A MRI/CT scan of the brain was requested if required to confirm the diagnosis, and patients were subsequently seen by the mental health team for older people, prescribed anti dementia medication as necessary, given the opportunity to participate in support groups, and to meet the dementia navigator from the Alzheimer's Society.

Results

Based on the search for presence of risk factors, 6657 (11.9%) people were identified from a total population of 55 845 above the age of 65 years. Invitation letters were sent offering an assessment, and 2762 (41.5%) expressed interest by contacting their GP practice. Those who expressed interest were then sent appointments for assessment at their GP practice by the SLNs. One thousand nine hundred and eighty (29.7%) physically attended the screening, and 358 (18.1%) individuals were screen positive and were reviewed by their GPs, who concluded that 205 (57.2%) of them were suitable for referral to the memory services for further assessment. Forty one (20%) people declined further assessment, and 164 (80%) individuals had comprehensive assessment at the secondary care level, conducted by the SLNs in their own homes or at the community mental health team office. Figure 1 shows the uptake of services at each stage of the diagnostic process.

The mean age of patients who had the comprehensive assessment was 82.3 years (SD=4.26), predominantly of white ethnic (160; 97.6%) background and male gender (110; 67.1%). Fifty four (32.9%) had mild cognitive disorder, and 101 (61.6%) patients were diagnosed with dementia. The most common dementia types were: mixed type (43; 42.6%) followed by Alzheimer's dementia (32; 31.7%). Eighteen (17.8%) patients had vascular dementia, seven (6.9%) patients had dementia associated with Parkinson's disease, and one (0.99%) patient had Lewy Body dementia. The median time taken for patients to receive a diagnosis was 64 (42-81) days. During this time period, patients underwent assessments at the primary care and secondary care level, blood tests, and review by a consultant psychiatrist. Table 1 summarises these findings.

Risk factors

Eighty eight (56.7%) patients had multiple co-morbidities. The most common risk factor among patients with cognitive impairment (MCD or dementia) was hypertension (69; 44.5%), followed by heart diseases (64, 41.3%). Forty five (29.03%) had a history of stroke and 37 (23.9%) had diabetes.

Increasing diagnosis rates of dementia

This project identified 101 new patients with dementia in a period of 18 months, thus improving the diagnosed proportion from 49 to 52%.

See supplementary file: ds6456.docx - "Figure 1"

Lessons and limitations

This study aimed to improve the diagnosis rates by using simple screening tools among people with dementia risk factors, and identifying people with dementia who were not yet diagnosed. In this project specialist link nurses worked across primary and secondary care services, providing a collaborative approach in identifying patients, and completing the assessments.

Identifying mild cognitive disorder

1. 9% of patients who completed the assessment were diagnosed with MCD, which is considered to be a risk factor for developing dementia. Approximately 11-33% of those diagnosed with minimal cognitive impairment convert to dementia over a two year period.⁽²⁷⁾ Identification of people who are at a high risk of developing dementia may enable them to consider risk reduction strategies, including smoking cessation, adequate control of blood pressure, diabetes, and hypercholesterolemia. Life style modifications like controlling obesity, regular exercise, and healthy eating become particularly important in this group. Through this project, for patients identified as having MCD, flags were placed in GP electronic records, so that GPs could refer them to secondary services should they show a further decline in cognitive functioning.

Diagnostic accuracy of screening instruments and process

Among the 358 individuals who were screened positive, 155 (43%) received a diagnosis of mild cognitive disorder or dementia. By contrast, 155 of the 205 (76%) referred by their GP received a clinical diagnosis, as did 95% of the 164 who completed a specialist assessment. Mini-Cog is a well accepted, easy and quick (one and a half to three minutes) test to administer.⁽²⁸⁾ Our results support the already established finding of the effectiveness of combined use of a brief cognitive screening test (Mini-Cog), along with a measure of functional ability (FAQ) to discriminate between cognitively normal elderly people, those with mild cognitive impairment, and those with dementia.⁽²⁹⁾

Role of specialist link nurses

This study shows that cognitive and functional assessment of

patients who are at a high risk of developing dementia, and who respond to a screening invitation by trained interviewers in primary care, does identify patients with as yet undiagnosed dementia. Brief assessment by trained interviewers will also provide a suitable alternative to screening by busy GPs, who should instead enhance their diagnostic skills, aiming to recognise the features of dementia syndrome as it emerges in individual patients, and acquire the repertoire of responses that serve the best interests of their patients, and of family carers.(30,31)

This study does not give enough information about those who declined to take part after expressing interest, and those who dropped out of the process after assessment; the characteristics of these individuals deserve further investigation. Nor does this study measure the benefits or harms of earlier recognition of dementia, which requires an experimental study.

Ripple effects of the project

As a direct result of the project, 101 new patients with dementia were diagnosed. However during the project period there was a notable increase of 27% in the total number of referrals with suspected dementia to the secondary care services, and the total number of new diagnoses of dementia made in secondary care during this period was 482. The project became a part of the Dementia Enhanced Services for GPs, which came about at the same time. We believe the GP training days, dementia road shows, and the part played by the SLNs, in educating and increasing the awareness of dementia among GPs by their presence in primary care, may have contributed to this increase. During this period the diagnosis rates in Surrey Downs based on Surrey and Borders NHS partnership electronic patient records has increased from 49 to 62.5%. This is not reflected appropriately in the dementia prevalence calculator, due to lack of data harmonization between the two registers.

Project costs

Project funding of £249 000 was secured for a year from the Prime Minister's dementia challenge fund in January 2013, with an aim of diagnosing up to 300 dementia patients. Most of the expenditure was for staffing and administration of the project. 101 new patients were diagnosed with dementia directly through the project, costing £2465 per case (including the whole assessment process). The project manager did a lot of work with GP electronic patient records to identify the "at risk" cases. This data screening process took nearly three months, with visits to individual GP practices to collect data. It also needed the logistical support from CCGs to provide a place to access and store records, send letters to the patients identified as "at risk", receive and log their phone calls, and book the screening appointment with the nurses.

Patient satisfaction survey

A patient satisfaction survey was conducted by the project manager by sending letters to those people who attended the screening at their GP practice. Most of those who responded rated the project as Good or Excellent. Many valued the project based on its

accessibility, as well as an opportunity they had received to make sure that they do not suffer from significant cognitive decline.

Conclusion

The size of the target population and attention to people who were at risk of developing dementia are the strengths of this study. This project also served as background work for a commissioning model which suggests using expertise within dementia diagnosis services to provide in reach to primary care, to develop staff skills in identifying possible dementia, and to improve the quality of referrals. This model offers a seamless service by making secondary care skills available to primary care. The participants had their initial assessment in a less stigmatizing environment, which is possibly a factor that promotes attendance.

We did not aim to test the psychometric properties of the "screening" as a test, however, which is a limitation of this methodology. Assessment of randomly selected individuals who were screened negative at the secondary care level, to assess measures of sensitivity and specificity, would be a way forward.

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Declaration of interests

Nothing to declare.

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Ethical approval

According to local trust policy, this project was deemed to constitute quality improvement not requiring formal ethics approval. Information governance agreements were signed between various agencies to access and share information.