Assessment and management pathways of older adults with mild cognitive impairment: descriptive review and critical interpretive synthesis

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Scientific summary

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Scientific summary

Background

Mild cognitive impairment (MCI) is defined as objective cognitive symptoms (e.g. memory problems) in the absence of dementia. MCI is common in older people, affecting 20% of those aged > 65 years. Although most people with MCI do not go on to develop dementia, the condition is associated with increased dementia risk. This may lead people with memory problems to seek help from health services. People with MCI may also be identified as a result of treatment for other conditions in a range of settings.

The concept of MCI as a stage that is intermediate between normal cognition and dementia has been in widespread use among specialists since the 1980s, with subsequent uptake in primary care. In the UK, the 2009 National Dementia Strategy and associated Prime Minister's challenge emphasised the importance of prevention and prompt diagnosis, both of which involve a focus on people with MCI and other memory problems. The responsibility for prevention of dementia and support for people with the condition is divided between public health, the NHS and social care, although recent policy increasingly favours the integration of health and social care. Health and social care are devolved matters, with some differences between the nations of the UK.

Access to services for people with MCI is a complex issue. Lifestyle changes can reduce modifiable risk factors for dementia, but there appear to be no evidence-based interventions aimed specifically at preventing dementia that are suitable for delivery on a large scale. The responsibility for preventing dementia also falls into a grey area between public health (i.e. the responsibility of local authorities) and the NHS. NHS memory services are limited to people with a diagnosis of dementia and are unable to help those with MCI, beyond 'signposting' to other services.

The current configuration of services leads some health professionals to question the value of identifying people with MCI. These health professionals argue that a 'label' of MCI may worsen anxiety or other mental health problems, without offering access to effective treatments that are not otherwise available. On the other hand, prevention of dementia is a high priority for those directly affected and society as a whole.

In 2017, the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research (HSDR) programme issued a call for research into cognitive impairment. In view of a limited response, the HSDR programme team went on to request that the Sheffield HSDR Evidence Synthesis Centre review the current evidence base, taking different perspectives into account, to identify key implications for research and service delivery.

Objectives

The review addresses the following questions:

- What is the evidence base around the assessment and management pathway of older adults with MCI in acute hospital wards, community/primary care and residential settings? In particular –
    - How are older adults presenting with memory problems investigated to understand the underlying cause of impairment?
    - What are the advantages and disadvantages of a 'diagnosis' of MCI? (We will aim to address both patient and health/social care provider perspectives.)
    - What is known about the experience of health and care services from the perspective of people with memory problems and their support networks (e.g. family, friends and other carers)?

Methods

Patient and public involvement

Patients and the public were involved through the Evidence Synthesis Centre Strategic Public Advisory Group and a topic-specific advisory group. The topic-specific advisory group provided input on their experience of services for people with MCI and the advantages and disadvantages of MCI as a diagnostic label. Near the end of the review, there was a second meeting at which the group commented on the review findings and were involved in writing the *Plain English summary*.

Data sources

In January 2021, we searched MEDLINE, EMBASE, PsycInfo®, Scopus, Cumulative Index to Nursing and Allied Health Literature, The Cochrane Library (i.e. Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials), Science Citation Index and Social Science Citation Index. The search was limited to studies published in English between 2010 and 2020. Grey literature and citation searches were also performed.

Inclusion criteria

Participants

Participants were older adults (likely to be aged ≥ 60 years or ≥ 65 years), with memory problems, with or without a diagnosis of MCI, and relevant health and social care professionals, family caregivers and volunteers.

Interventions

Interventions included screening and assessment tools (including staff training), management pathways and service models for people with MCI.

Comparator

The most relevant comparator was no treatment/standard care. Quantitative studies with and without a control/comparator group were included when they met other criteria.

Outcomes

Outcomes of interest included quality of life, mental health and other patient/carer outcomes, as well as health system outcomes (e.g. measures of costs/resource use).

Study designs

Study designs that were included were quantitative research studies of any design; qualitative research involving, for example, interviews and focus groups; mixed-methods studies; service evaluations (from the UK only); UK-relevant guidelines; policy documents and grey literature; and systematic and narrative literature reviews.

Context/setting

Studies with a health and social care context/setting, including acute hospital wards, community/primary care and residential settings, were included. Although the main focus was the UK, studies from other Organisation for Economic Co-operation and Development countries were included to address gaps in the UK evidence base.

Other criteria

Other criteria included studies published after 2010 and grey literature from the UK.

Exclusion criteria

- Studies in which people had a formal diagnosis of dementia.
- Lifestyle interventions intended to reduce the risk of developing dementia.
- Editorials, commentaries, news and discussion articles, unless they provided full details of a service or pathway.
- Books and book chapters, theses, articles in professional magazines and conference abstracts.

Study selection

Search results were downloaded to a reference management system (EndNote X9.2, Clarivate Analytics, Philadelphia, PA, USA) and duplicates removed. Unique references were imported into EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, London, UK) systematic review software for screening and analysis. Titles/abstracts of imported references were screened against the inclusion criteria by four members of the review team (DC, AB, AC and KS), with any queries resolved by discussion. A 10% sample of excluded references were checked by one of the reviewers to ensure consistency and guard against premature exclusion. References that appeared potentially relevant were screened as full-text documents for a final decision on inclusion or exclusion, with any uncertainties resolved by discussion among the review team.

Data extraction and quality assessment

Key data were extracted and tabulated from the included studies, including study type, area of study, population, setting, study methods, findings, conclusions and key limitations. For the critical interpretive synthesis (CIS), data extraction included positioning in argument, cited affiliations, study methods and CIS themes. Data extraction was undertaken using the coding and reporting functions of EPPI-Reviewer 4. Data extraction was performed by the four reviewers (DC, AB, AC and KS) and a 20% sample of each other's work was checked.

Quality (risk-of-bias) assessment was undertaken for all studies that use a recognised design for which an appropriate quality assessment tool is available. Quality assessment tools used in this review included the Joanna Briggs Institute checklist for quasi-experimental studies, the CASP (Critical Appraisal Skills Programme) tool for qualitative studies, AMSTAR (A MeaSurement Tool to Assess systematic Reviews) for systematic reviews, the Swedish Agency for Health Technology Assessment tool to assess methodological limitations of qualitative evidence synthesis, and risk of bias for cohort/cross-sectional studies and diagnostic studies from the National Heart, Lung and Blood Institute (Bethesda, MD, USA) and Cochrane Collaboration, respectively. Quality assessment was performed by the four reviewers (DC, AB, KS and AC), who checked a 20% sample of each other's work.

Data synthesis

We performed two separate evidence reviews: (1) a descriptive review with narrative synthesis, focusing on diagnosis, service provision and patient experience; and (2) a CIS of evidence on the advantages and disadvantages of MCI as a diagnostic label. Review 1 incorporated evidence from primary studies supplemented by systematic reviews. Included studies were allocated to one or more of the following groups for a narrative synthesis: conceptual studies, screening and diagnosis, services and pathways, and/or patient/carer experience.

In review 2, quantitative and qualitative evidence was synthesised using methods based on the principles of CIS. Briefly, CIS is a synthesis approach designed to analyse diverse sources and use analytical outputs to develop a conceptual framework. The variant of CIS that we used involved mobilising the literature to construct two alternative conceptual frameworks (i.e. one that assumes that a definitive diagnosis of MCI plays a pivotal role and the other that progresses a management pathway in the absence of a definitive diagnosis).

Results

A total of 122 studies were included in the descriptive review, of which 29 were also included in the CIS. Follow-up searching identified a further 11 studies for the CIS. The screening/diagnosis study group was largest, followed by the group of studies of services and pathways. The majority of quantitative studies used a cohort or cross-sectional design, although a few cluster-randomised trials were also included. The quality of cross-sectional and cohort studies varied widely, with common issues being small samples, lack of blinded outcome assessment and adjustment for confounders.

Qualitative studies of patient/carer experience tended to be rated as being of higher quality than the quantitative studies, although some were small. Other qualitative studies dealt with experiences of specific groups, limiting the generalisability of the findings. Study participants were most commonly recruited from populations of community-living older adults or those who had sought medical help from their general practitioner (GP) for memory problems.

The descriptive review identified multiple barriers to efficient diagnosis of memory problems, starting with patient reluctance to seek help. Interventions to encourage people with concerns about their memory to see their GP have been evaluated, but without clear evidence of effectiveness. GPs have a variety of cognitive tests available, but recent evidence suggests that substantial numbers of patients meeting criteria for dementia do not have a diagnosis recorded. Patients may be referred to a memory clinic, but these clinics are mainly intended to identify and support people with dementia, and people with MCI may be discharged back to their GP until symptoms worsen. The review identified considerable variation in the way memory clinics in the UK are organised and their approach to investigating the underlying cause of memory problems. During the COVID-19 pandemic, memory clinics have changed their ways of working to incorporate virtual assessments, with uncertain consequences for patient care. Availability of scanning and biomarker tests to identify early dementia in routine UK practice is patchy. We found strong evidence from qualitative studies that patients with MCI and their carers find the process of investigation and diagnosis difficult and frustrating to negotiate. Receiving a diagnostic label of MCI involves living with uncertainty and the terminology itself may be problematic for patients.

The key finding from the CIS was that the need for a ‘timely’ diagnosis outweighs the ongoing debate about the value, or otherwise, of early investigation and labelling of memory problems. Determining what is a timely diagnosis involves balancing the perspectives of the patient, the health system and the clinician.

Conclusions

The concept of MCI as a state between normal ageing and dementia has been in use for many years. In practice, the diagnostic label of MCI is applied to people with a variety of underlying conditions whose cognitive status may decline, remain stable or improve over time. Evidence included in review 2 suggests that the label is valued by clinicians, but is more problematic for patients and their carers.

Investigation of memory problems normally starts when people seek help from their GP. Delays in seeking help after noticing symptoms are common and members of ethnic minority groups may face specific barriers to help-seeking.

Evidence suggests that GPs may have difficulty recognising and recording memory problems using clinical judgement alone. Screening with cognitive tests may be a good use of resources (Poppe M, Mansour H, Rapaport P, Palomo M, Burton A, Morgan-Trimmer S, *et al*. ‘Falling through the cracks’; Stakeholders’ views around the concept and diagnosis of mild cognitive impairment and their understanding of dementia prevention. *Int J Geriatr Psychiatry* 2020;**35**:1349–57. https://doi.org/10.1002/gps.5373) and is likely to be of increasing importance with the development of disease-modifying treatments that may benefit people in the early stages of dementia. Further investigation involves tests that are generally available at specialist centres only (e.g. magnetic resonance imaging or positron emission tomography, and analysis of biomarkers in blood and cerebrospinal fluid).

Pathways for people with memory problems may involve follow-up in primary care or referral to a memory clinic/service. Memory clinics are primarily commissioned to identify and support people with dementia, suggesting that different service models may be needed for people with MCI. The lack of an evidence-based population-level dementia prevention programme may be a barrier to developing such services.

People with MCI interviewed for qualitative studies frequently portrayed their experiences prior to diagnosis in negative terms. The findings suggest a need for research and practice to make the investigation and management of MCI more patient centred.

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Implications for service delivery

We identified the following implications for service delivery:

- Services should consider the potential value of efforts to improve the recording of diagnoses of dementia in primary care (e.g. by provision of training).
- Quality improvement work at a local and national level is expected to produce benefits in terms of improving and standardising services provided in memory clinics.
- Our results suggest the need for formalised discussion between GPs and their patients with memory problems prior to memory clinic referral, covering the implications of dementia as a possible diagnosis.
- The Manchester consensus guidance identified a need for National Institute for Health and Care Excellence guidance on diagnosis and management of MCI, and such guidance could reduce variation in service delivery. Although national guidance is useful in terms of setting evidence-based standards, local services will need to construct flexible diagnostic disclosure pathways.
- Changes to the operation of memory clinics necessitated by the COVID-19 pandemic will require evaluation to ensure that services are delivered efficiently and effectively in the aftermath of the pandemic.
- Services will require detailed planning and resourcing if they are to optimise the delivery of disease-modifying therapies should such therapies be approved for use in the NHS. This is a priority for both service delivery and research.

Implications for research

We identified the following priorities for research:

- The descriptive review identified limited research on screening for memory problems outside general practice. Research to evaluate models of service for other settings, such as emergency departments, acute hospital wards and care homes, would be of value.
- There is a need to strengthen the evidence base for primary care-led investigation and management of memory problems compared with service delivery through hospital-based memory clinics.
- In view of the move towards remote delivery of health care forced by the COVID-19 pandemic (Collins R, Silarova B, Clare L. Dementia primary prevention policies and strategies and their local implementation: a scoping review using England as a case study. *J Alzheimers Dis* 2019;**70**:S303–18. https://doi.org/10.3233/JAD-180608; Dunne RA, Aarsland D, O'Brien JT, Ballard C, Banerjee S, Fox NC, *et al.* Mild cognitive impairment: the Manchester consensus. *Age and ageing* 2020. https://doi.org/10.1093/ageing/afaa228), research is needed to evaluate remote methods of memory assessment as part of mainstream services, as well as for remote locations.
- As noted above, research is needed to optimise the introduction of disease-modifying treatments for early dementia on approval. This could build on modelling work already completed to estimate the costs of increased use of scanning and biomarkers, including equipment and training costs.

- Research should continue to develop and evaluate evidence-based programmes to reduce dementia risk that can be implemented at scale for people with MCI, taking into account the needs and preferences of people with MCI.
- Further qualitative research is needed to ensure that services for people with memory problems are patient centred and provide people with a timely diagnosis expressed in terms that they can understand and on which they can act. This research should include people with diverse memory problems (e.g. subjective cognitive decline and functional cognitive disorder, as well as MCI) and different underlying causes for those diagnosed with MCI.

Study registration

This study is registered as PROSPERO CRD42021232535.

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This report

The research reported here is the product of an HSDR Evidence Synthesis Centre, contracted to provide rapid evidence syntheses on issues of relevance to the health service, and to inform future HSDR calls for new research around identified gaps in evidence. Other reviews by the Evidence Synthesis Centres are also available in the HSDR journal.

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