A systematic rapid evidence assessment of late diagnosis

This systematic rapid evidence assessment identifies the nature and extent of the literature on late diagnosis across a range of conditions.

Key words: late diagnosis

The review was carried out by the **Institute of Education's Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre)** in 2012. It was commissioned and funded by the Policy Research Programme in the Department of Health.

Key findings

Findings are of interest to policy makers, clinicians, general practitioners and patients.

- Late diagnosis is of concern for those with chronic obstructive pulmonary disease (COPD), dementia, human immunodeficiency virus (HIV) and type 1 Diabetes.
- COPD has a high prevalence of late diagnosis, with an estimated 80% of cases remaining undiagnosed. Many of these cases are patients in the milder stages of the disease.
- Early dementia is hard to detect, with doctors acknowledging their difficulties in distinguishing between dementia and 'normal ageing'.
- The evidence suggests that a substantial proportion (16–51%) of children experience delayed diagnosis in type I diabetes.
- Those engaging in high-risk behaviours were more likely to avoid HIV testing due to fear of a positive diagnosis, with worrying implications regarding onward transmission. Data from the Health Protection Agency indicates that 50% of new diagnoses are late in the UK.
- Broadly, late diagnosis affects vulnerable groups such as older people or those living in poverty.
- Patients delayed seeking help from clinicians for a number of conditions including chronic kidney disease, dementia, HIV, stroke, myocardial infarction, epilepsy and tuberculosis. Late presentation was linked to symptom misinterpretation and lack of knowledge.
- Inadequate knowledge and training of doctors were barriers to prompt diagnosis for chronic kidney disease, COPD, dementia and tuberculosis.
- Restricted access, insufficient consultation time and resource constraints hindered diagnosis.
- There was very little material about the cost implications of delayed diagnosis.

What we did

Delayed diagnosis results in serious consequences for patients and healthcare professionals and can incur substantial financial costs. While research focusing upon cancer suggests that late diagnosis leads to increased morbidity and mortality, the evidence for other conditions is less clear. This systematic rapid evidence assessment (SREA), an exhaustive overview and summary of existing high quality research evidence relevant to a research question, identifies the nature and extent of the literature on late diagnosis across a range of conditions. We wanted to know:

- What is the prevalence of late diagnosis?
- What are the determinants of late diagnosis?
- What are the outcomes of late diagnosis?
- What are the cost implications of late diagnosis?

- Which interventions reduce delays in diagnosis?

How we did it

We examined evidence from 43 systematic reviews for: chronic kidney disease, dementia, depression, type I diabetes, epilepsy, HIV, myocardial infarction, psychosis, stroke and tuberculosis.

We found 606 UK primary studies on late diagnosis, of which 12 investigated COPD, 12 investigated tuberculosis and 4 investigated epilepsy. While there were systematic reviews to draw on for most conditions, this was not the case for COPD (no systematic reviews), tuberculosis (systematic reviews with limited relevance to UK healthcare system) and epilepsy (systematic reviews focused on over-diagnosis), and so we used evidence from the primary studies.

Implications

The training of doctors in the early diagnosis of COPD, dementia and tuberculosis has improved detection. Media campaigns to alert the public to the symptoms of stroke, heart attack and psychosis have had mixed results. Overall, public recognition has increased, but this may not have contributed to shortening patient delay.

This study includes information from health care systems outside the UK. However, policy makers may find future reviews of UK primary research into the late diagnosis of these conditions useful to understand the nature of the problem in a UK context.

Further information

For the full report see 'A systematic rapid evidence assessment of late diagnosis'

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