

# VU Research Portal

## Diagnosing mild cognitive impairment and dementia in primary care

van den Dungen, P.

2016

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### **citation for published version (APA)**

van den Dungen, P. (2016). *Diagnosing mild cognitive impairment and dementia in primary care*.

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

## Summary

The burden of dementia on societies worldwide is increasing. Several studies suggest that dementia is regularly not diagnosed by general practitioners (GPs); and that pro-active integrated primary care for persons with dementia and their relatives is often lacking. We reviewed the international literature on the accuracy of GPs' dementia diagnoses at different severity stages. In addition, we reviewed the literature on preferences regarding disclosure of a diagnosis of dementia of the general population and of people with cognitive impairment. Furthermore, we investigated Dutch GPs' awareness of cognitive impairment among older persons in their practices. Finally, we studied the effects of an intervention designed to facilitate diagnosing mild cognitive impairment (MCI) and dementia by GPs, and to improve subsequent care.

### **Accuracy of general practitioners' dementia diagnoses at different severity stages**

To estimate the accuracy of GPs' dementia diagnoses at different stages of dementia, we performed a systematic literature review (**chapter 2**). Our search yielded six relevant articles. The included studies used different methods to establish whether GPs had diagnosed dementia. Studies on diagnoses registered in the medical records and on diagnoses recollected and indicated on a list (these studies concern all registered older patients) found that GPs diagnosed up to a third of persons with mild dementia, and a third to more than half of persons with moderate to severe dementia. There were few false positive diagnoses. Studies measuring diagnostic accuracy during consultation reported a wide range of detection rates for mild dementia. However, more than two thirds of persons with moderate to severe dementia presenting for consultation were diagnosed. With this method (that includes only persons presenting for consultation), there were somewhat more false positives. In conclusion, a low rate of false positive dementia diagnoses in general practice comes at the price of a high rate of underdiagnosis, especially for the mild dementia spectrum.

### **Preferences regarding disclosure of a diagnosis of dementia**

To quantify preferences regarding disclosure of people without and with cognitive impairment, we searched the literature for studies on this topic, reviewed these studies systematically and performed a meta-analysis (**chapter 3**). In addition, we extracted arguments in favour of and against disclosure. Our search yielded 23 relevant articles including preferences of 9,065

respondents. Pooling of the preferences of persons without cognitive impairment showed that nine out of 10 persons would want to be informed if they would have dementia in the future. Among people referred to a memory clinic or diagnosed with dementia 8 to 9 out of ten people wanted to be informed about the diagnosis. The most frequently expressed arguments in favour of disclosure pertained to autonomy and the possibility to plan one's future. The most frequently expressed arguments against disclosure were the fear to get upset and that knowing has no use. In conclusion, the vast majority of individuals without, and with cognitive impairment wanted to be informed about a diagnosis of dementia for reasons pertaining to autonomy.

### **Dutch general practitioners' awareness of cognitive impairment among older persons not diagnosed with dementia**

To assess GPs' awareness of cognitive impairment we compared their evaluation of the absence or presence of cognitive impairment in older persons without an established diagnosis of dementia with a reference test of cognitive functioning. In addition, we assessed which patient characteristics were associated with con- and discordance between GPs' evaluation of cognition and results of the reference test (**chapter 5**). The reference test confirmed the presence of cognitive deficits in almost half of persons labelled to have 'possible cognitive impairment or dementia' by GPs. The reference test contradicted the absence of cognitive deficits in one out of eight people labelled to have 'no signs of cognitive impairment' by GPs. The label 'possible cognitive impairment or dementia' was more often confirmed by the reference test among persons who were dependent on others for their activities of daily living. The chance that the label 'no signs of cognitive impairment' was contradicted by the reference test was higher among the oldest old. In conclusion, one in two cases where GPs assumed cognitive impairment were false positives, while one in eight assumed cognitively normal cases turned out to have cognitive impairments. Especially GPs' unawareness of cognitive impairment in older persons may explain a substantial part of missed dementia diagnoses in primary care.

### **Case finding of mild cognitive impairment and dementia and subsequent care in Dutch general practices**

In a cluster randomised controlled trial we assessed the effect of a two-component intervention of case finding and care on 1) the number of new diagnoses of mild cognitive impairment and dementia, and 2) the mental health of older persons consenting to

participate in the second stage of the trial and their relatives (**study design in chapter 4; results in chapter 6**). The study was performed in 15 primary care practices, among 647 persons ( $\geq 65$  years) in whom GPs suspected cognitive impairment but without a formal diagnosis of dementia. The first component of the intervention was training GPs to diagnose mild cognitive impairment and dementia. The second component was case finding by a trained practice nurse (PN) and the GP and subsequent care when indicated. Control practices provided care as usual. Only a fourth ( $n = 145$ ) of eligible persons wanted to participate in the second stage of the trial: assessment and care by the PN or usual care. We found a non-significant increase in the number of mild cognitive impairment cases favouring the intervention. There were no differences in the mental health of older study participants or their relatives between the intervention and control group. In conclusion, the tested intervention led to a non-significant increase in mild cognitive impairment diagnoses and had neither beneficial nor detrimental effects on the mental health of older persons participating and their relatives.

### **Overall conclusion**

GPs' awareness of the cognitive status of their older patients seems to be limited. This may be an important explanatory factor for underdiagnosis of dementia in primary care. Nine out of ten people would prefer to know the diagnosis if they would have dementia. However, the extent to which such preferences predict actual help seeking behaviour when there is cognitive decline is unknown. Our study on case finding of MCI and dementia and subsequent care showed no favourable effect on the diagnostic rate or on the mental health of older persons with possible cognitive impairment or that of their relatives. Reasons for this null finding may be the targeted population, the low participation rate and the implementation of the intervention. New research is needed to assess whether improved case finding of dementia might still be beneficial in terms of support, care and empowerment for persons with declining cognitive functioning and their carers. For now, we encourage open diagnostic counselling and proactive diagnostic assessment when patients present with possible cognitive impairment.