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Diagnosing mild cognitive impairment and dementia in primary care

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Chapter 7

General discussion

In this thesis we have focused on current practice of diagnosing dementia in primary care, patient preferences regarding disclosure and the evaluation of an intervention to improve the detection and management of mild cognitive impairment (MCI) and dementia in primary care.

We searched the literature for studies on the diagnostic accuracy of general practitioners' (GPs) dementia diagnosis at different stages of dementia and reviewed these studies systematically (chapter 2). In addition, we searched the literature for studies quantifying preferences regarding disclosure of a diagnosis of dementia of persons with and without actual cognitive decline. We reviewed these studies systematically and performed a meta-analysis. Moreover, we summarized the most frequent arguments in favour of, and against disclosure (chapter 3). We designed and carried out a cluster RCT to test a newly designed intervention, aimed to improve the detection and management of MCI and dementia in primary care, in collaboration with two primary care cooperatives (chapter 4). Before the start of this trial, GPs classified the cognitive functioning of all their patients aged 65 years and above. To assess GPs' awareness of cognitive impairment among older persons in their practices we compared their labels 'possible cognitive impairment or dementia' and 'no signs of cognitive impairment' to a reference test of cognitive functioning (chapter 5). Finally, we present the results of the cluster RCT testing the new intervention aimed to improve the detection and management of MCI and dementia in primary care. We discuss potential explanations for the absence of significant effects, and implications for future research and clinical practice (chapter 6).

In this final chapter, we present the main findings of our research, followed by a discussion of the limitations and methodological issues and the implications for clinical practice and future research.

Main findings in the context of current evidence

The accuracy of general practitioners' dementia diagnoses at different stages of dementia

We performed a systematic literature review that included studies comparing GP diagnoses of dementia to a validated reference standard for the diagnosis of dementia. We decided not to perform a meta-analysis of included studies because of substantial methodological heterogeneity. In studies of *documented* ($n = 3$) diagnoses and studies of *recollected* ($n = 1$)

diagnoses, the sensitivity of GPs' diagnoses of 'dementia' was 14 - 33 % for mild dementia and 28 - 61 % for moderate to severe dementia. The sensitivity of the combined diagnostic categories of 'cognitive impairment' and 'dementia' was 48 - 67 % for mild dementia and 76 - 85 % for moderate to severe dementia. Specificity was excellent for all severity stages in both analyses. Compared with recollected and documented diagnoses, the sensitivity of diagnoses established *during consultation* (n = 3 studies) was higher, but the specificity lower. In conclusion, roughly half of individuals with moderate to severe dementia were not diagnosed. No more than a third of individuals with mild dementia was diagnosed.

Other authors did perform a meta-analysis of studies of GPs' diagnostic accuracy, despite substantial methodological differences. Their results confirm our finding that the sensitivity of diagnoses documented in medical records is lower, and specificity higher, compared to diagnoses established during consultation (pooled sensitivity 37.9%; and specificity 90.5%, for documented diagnoses; pooled sensitivity 73.4%; and specificity 75.5%, for diagnoses during consultation)¹. In addition, it showed that dementia severity is an important predictor of diagnostic accuracy, with sensitivity being lower for mild dementia. However, the pooled sensitivity to detect both mild and moderate to severe dementia was somewhat higher than what we found and the specificity somewhat lower. A more recent study still found substantial under-documentation of dementia diagnoses in primary care medical records².

Preferences regarding disclosure of a diagnosis of dementia of people with and without cognitive impairment

Systematic review and meta-analysis of the literature on this subject showed that among persons with no cognitive impairment, the pooled percentage favouring disclosure was 90.7% (95 %-confidence interval: 83.8 - 97.5 %; 15 studies). Among persons referred to a memory clinic or already diagnosed with dementia, the pooled percentage favouring full disclosure was 84.8% (95 %-CI: 75.6 - 94.0 %; eight studies). The most frequently reported arguments in favour of disclosure were that people wanted to know what was going on with them and that they wanted to be involved in care planning. Other reasons were that knowing the diagnosis enabled them to look for treatment options and obtain information about the disease and about available services. Reasons against disclosure were therapeutic nihilism and the fear of negative psychological effects of knowing. Strikingly, the possibility of suicide was mentioned both as a reason for and against disclosure. Still, only individuals without cognitive impairment mentioned this argument.

Another systematic review did not meta-analyse data, but reports figures consistent with our findings and so do more recent studies^{3,4}. Further, a vast body of evidence shows that caregivers generally also perceive mostly benefits and few disadvantages of disclosure of the diagnosis to the patient they care for⁵. The authors of the above mentioned systematic review observe a shift in the discussion from whether to disclose, to how to disclose³. In accordance with one of the studies in our review, a more recent study reported that numbers favouring disclosure did not decline significantly after persons were informed about potential risks and benefits of diagnosis and disclosure⁶. However, in this study numbers favouring diagnostic assessment did decline after receiving such information.

Awareness of Dutch GPs of cognitive decline in older persons without a diagnosis of dementia

Twenty-nine GPs classified the cognitive status of all their patients aged ≥ 65 years or above ($n = 7,865$) into four categories, based on recollection and the medical records. We compared their cognitive labels 'possible cognitive impairment or dementia' (8.3 % of persons) and 'no signs of cognitive impairment' (83.7 % of persons) with a reference test of cognitive functioning (the CAMCOG). We did not validate the two other labels 'probable dementia' (3.6 % of persons) and 'unknown' (4.5 % of persons).

The positive predictive value of the GPs' label 'possible cognitive impairment or dementia' for a CAMCOG score suggestive of dementia or MCI was 47.1 % (95 %-CI: 43.5 – 62.4 %). The 1-NPV of their label 'no signs of cognitive impairment' for a CAMCOG score suggestive of dementia or MCI was 12.5 % (95 %-CI: 8.2 – 16.8 %). The odds that GPs were unaware of the presence of cognitive impairment were higher in older elderly (OR 1.15 [95 %-CI 1.09 – 1.23] per year). The odds that GPs were correctly aware of the presence of cognitive impairment were higher among persons depending on others in their activities of daily living (ADL) and/or instrumental ADL (OR 2.24 (95 %-CI 1.16 – 4.35) and 1.69 (95 %-CI 1.26 – 2.27), respectively).

Our study focused on persons without an established diagnosis of dementia because we wanted to know which proportion of persons in whom GPs had noticed no signs of cognitive impairment, did have cognitive impairment. In addition, we were interested to know whether GPs were also over-aware; mislabelling people as having cognitive impairment when actually they had not. There are no studies to which we can compare our findings,

since, to our knowledge, all previous studies included prevalent dementia cases in their estimates of the positive and negative predictive value of GPs' diagnostic labels. Our finding that ADL dependency was associated with detection of dementia is consistent with previous findings^{7,8}. Previous studies report contradicting findings about whether higher age is associated with GPs being unaware of cognitive impairment^{9,10}.

Case finding of mild cognitive impairment and dementia and subsequent care

In a primary care based cluster RCT we tested how a two-component intervention of case finding and care impacted the rate of new MCI and dementia diagnoses and the mental health of older persons participating and their relatives. The trial was run in 15 primary care practices, among 647 persons (≥ 65 years) in whom GPs suspected cognitive impairment, but who were not diagnosed with dementia. The first component of the intervention consisted of a training FPs to diagnose mild cognitive impairment (MCI) and dementia. In addition, they learned about the study protocol and how to collaborate with the study practice nurse. The second component of the intervention consisted of the study practice nurse performing case finding by means of a combined functional and cognitive assessment of older persons in whom GPs suspected cognitive impairment. If this assessment suggested MCI or dementia, this prompted referral to the GP for further diagnostic evaluation. If the established a diagnosis of dementia or if there was MCI and a need for additional care, a more extensive geriatric assessment and further care were offered. The primary outcome was the rate of new diagnoses of MCI and dementia after 12 months. This was assessed among all persons in whom GPs suspected cognitive impairment ($n = 647$). The secondary outcome was the mental health of patients and relatives consenting to participate in trial stage 2: intervention component 2 or usual care ($n = 145$).

Seven PCPs were randomized to intervention and eight to control condition. We found that, after one year, MCI or dementia was diagnosed in 42.3% (138/326) of persons in the intervention, and in 30.5% (98/321) in the control group (estimated difference GEE: 10.8%, OR: 1.51, 95%-CI 0.60 – 3.76). There were no differences in mental health between the intervention and control group, among patients and relatives who consented to stage 2 of the trial ($n = 145$; 25%),

In conclusion, we found a non-significant difference in the number of new MCI diagnoses and no difference in new dementia diagnoses. The intervention had no beneficial, but also no detrimental effect on mental health of patients and relatives who accepted case finding and care.

This is the first study on case finding that targeted the entire group of registered patients in whom GPs suspected cognitive impairment or dementia. Other studies found that education and collaboration with a practice nurse increased the rate of (suspected) dementia diagnoses^{11–13}. Important differences are that in our study the prior chance of MCI or dementia was probably lower and there was no specialist involvement. To our knowledge, the current study was the first study to assess what effects case finding and subsequent care have on the mental health of patients and their relatives. A recent observational study showed that quality of life was higher among persons who knew they had dementia compared with persons who were unaware of it¹⁴.

Methodological considerations

Below, we discuss important methodological issues relevant to the interpretation of the studies in this thesis.

Systematic review of the accuracy of general practitioners' dementia diagnoses at different stages of dementia

Although overall the quality of the included studies was reasonable, there were limitations in the individual studies (e.g. blinding, reporting on missing data). Furthermore, some of the included studies were published over a decade ago, and thus do not reflect the current situation.

A striking difference between studies included in our review were the methods of establishing GP dementia diagnoses. These included searching medical records for diagnoses, having GPs indicate on a list of all older patients whether they had established a diagnosis, or asking them after a consultation whether they had diagnosed dementia. Thus, whether a diagnosis of dementia was established was operationalized in different ways in the studies. Notably, these different case ascertainment methods also imply different study populations (all older persons vs. persons presenting for consultation). In addition, the included studies used different reference standards for the diagnosis of dementia. All these differences threaten the internal validity of comparing between studies, and the validity of aggregating studies. Therefore, we chose to only summarize findings of studies with similar case ascertainment strategies.

Systematic review and meta-analysis of preferences regarding disclosure of a diagnosis of dementia

Although the results of this review are quite unequivocal, there are several methodological issues to be addressed. Perhaps the most important limitation of our review is that the studies among persons referred to memory clinics or diagnosed with dementia included a selected group of people, who are probably more receptive to, or even seeking for, a diagnosis. Therefore, their preferences cannot be generalized to all persons with (suspected) dementia. It is hard to estimate the magnitude of this potential source of bias. Another limitation present in studies among persons of this group is that it is unclear what the level of disease insight of respondents was, which makes it difficult to judge how thought-out their answer was. A limitation of the studies among persons without cognitive impairment was that the preference question concerned a hypothetical situation. Several studies show that people adapt to new circumstances and that preferences may change^{15,16}. Since longitudinal studies are lacking, not much is known about how cognitive decline may change preferences. Presumably, preferences may change in both directions; from wanting to know to not wanting to know, and vice versa. Moreover, respondents' notions about dementia may be limited and people's preferences may change after receiving information about dementia or about the pros and cons of disclosure. Such counselling was not offered in the majority of included studies. Finally, patients may give socially desirable answers when interviewed. Wanting to know may be the more socially desirable answer in a clinical or research setting.

Dutch GPs' awareness of cognitive decline among older persons without a diagnosis of dementia

The most important limitation of this part of our study was the low participation rate of patients with 'possible cognitive impairment or dementia' willing to undergo a complete reference test. A low participation rate threatens the external validity of a study because selective participation may occur. To assess whether such bias was present we performed a non-response analysis. We could not demonstrate selective response, but unfortunately we reached only a minority of non-respondents. Another study assessing non-response did find a lower response among patients with cognitive impairment¹⁷. In addition, our RCT provided an indirect indication that selective response might have occurred: the rate of MCI and dementia diagnoses by GPs after 12 months was higher among non-respondents than among respondents. If selective non-response of persons with cognitive impairment

did occur, this may have resulted in underestimation of the positive predictive value of GPs' judgment that cognitive impairment was present and in some overestimation of the NPV of their judgment that there were no cognitive deficits. Since the prevalence of cognitive impairment was substantially lower among persons whom GPs judged to have no cognitive impairment, the effect on the NPV is likely small.

Further, it should be noted that the reference test we used (the CAMCOG) is not a gold standard for the diagnosis of MCI or dementia. Although it has fair test characteristics to distinguish between normal ageing, MCI, and dementia, there are indications that it slightly overestimates the presence of dementia in a general population^{18,19}. Moreover, in our study, the stability over time of the CAMCOG at the individual level was limited. However, since total counts of patients with MCI and dementia remained stable over time, we assume this did not have a substantial effect on our estimates of GPs' awareness.

Case finding of mild cognitive impairment and dementia and subsequent care

We obtained the primary outcome (new dementia and MCI diagnoses after 12 months) among all patients in whom GPs thought that cognitive impairment or dementia might be present. However, only a quarter of patients and relatives consented to participate in stage 2 of the study, limiting the external validity of our results. Based on the reasons for not wanting to participate, this was not only due to the intervention but also for a substantial part to the burden of participating in a study.

Several reasons may explain the absence of a statistically significant difference in the number of new diagnoses between the intervention and control group.²⁰ First, among persons participating in stage 2 of the study the prevalence of MCI and dementia at baseline based on the CAMCOG was lower than we had estimated designing this study. This limits the potential effect of the intervention. Secondly, the impact of stage 2 of the intervention was likely modest: probably due to the limited sensitivity of the cognitive tests for MCI and earlier stages of dementia, the assessment by the practice nurses (PNs) yielded four times fewer suspected cases of cognitive impairment compared with the CAMCOG. In addition, less than three quart of persons consenting to stage 2 of the study were actually assessed by the PNs, and GPs did not always adhere to the clinical protocol. All these factors may have diluted a potential effect. Thirdly, it may be that GPs felt they still had too little to offer to patients in whom they suspected early dementia. Although dementia case management was offered in the region, other effective psychosocial interventions may not (yet) be sufficiently implemented within practices (e.g. information and support) or accessible in the

region (e.g. support groups, respite care). Fourthly, the contrast may have been decreased by efforts in the control practices. Some of the GPs and nurses providing elderly care working in those practices had a specific affinity with the subject of dementia. Finally, although the number of stage 1 participants exceeded the required sample size, a type II error cannot be fully excluded because we assumed a power of 70%. Another limitation is that the two-component intervention was rather complex, with components possibly also affecting each other, thus preventing assessment of the effectiveness of the separate components²¹.

The absent effect on mental health is most easily explained by there not being a statistically significant effect on the rate of MCI and dementia diagnoses, which diminished the potential impact of the support and care part of the intervention. Another explanation may be that the overall burden of (cognitive) disease on patients and relatives was still relatively low in this population²².

Implications for practice

Improving GPs' awareness of cognitive decline

We found that GPs were unaware of cognitive impairment in some of their patients, while in other patients they suspected cognitive impairment where there was none. Our findings suggest that unawareness of the presence of cognitive impairment may contribute substantially to the number of undiagnosed dementia cases in primary care. GPs may want to enquire about cognitive functioning more often. In addition, they may ask their team members to alert them when they notice signs of cognitive impairment in patients.

Case finding of MCI and dementia

At present, we cannot recommend to implement our intervention on a wider scale. Still, with increasing evidence about psychosocial interventions showing beneficial effects on the well being of dementia patients and caregivers we do recommend a more active approach to the diagnosis of patients with early stages of dementia. This is supported by the our finding that the majority of persons with dementia wishes to be informed about a diagnosis²³. Despite our null finding, we would recommend training GPs in dementia diagnosis and collaboration with nurses based on previous studies^{11,12,24}. Since the evidence about treatment options for MCI is still limited and because we could not demonstrate a positive effect of case finding we would not recommend the implementation of case finding of MCI as described in our study, at this stage^{25,26}.

Initial assessment and further diagnostic evaluation

As mentioned, the PNs' assessments yielded substantially fewer persons with possible cognitive impairment than there were identified by the CAMCOG. This suggests that the cognitive tests used have limited value in the detection of MCI and early stages of dementia. An advantage of this somewhat lower sensitivity is that it reduces the risk of false positive diagnoses. In addition, GPs can compensate this lower sensitivity by following-up on patients in whom they have a clinical suspicion of cognitive decline. We recommend to always integrate cognitive tests with clinical observation, a history and if possible a proxy history when patients or their relatives request for diagnostics, or when the GP deems further evaluation indicated. The use of standardised instruments that include a proxy history-based assessment of functioning (e.g. GPCOG) is recommended^{27–30}.

Communication about a diagnosis of dementia and MCI

People with dementia and their relatives often require help to find out about 'what is going on' with them, but may not ask for it³¹. Recent studies show persistent low rates of disclosure to persons with dementia^{32,33}. We suggest training GPs (e.g. reflection on own attitude, role plays) to become more comfortable with, and skilled in, diagnostic counseling, disclosure and subsequent support^{34–36}. One element of such education may be to correct GPs' overestimation of the harm of (correct) diagnostic labelling^{14,37,38}.

Still, reluctance to disclose should not be judged as inadequate too easily. Some persons with dementia have well thought-out arguments against disclosure (e.g. not wanting to live any more). In addition, when persons with dementia lack insight into their cognitive impairments, disclosure to the patient may only cause confusion or anxiety. In this respect, balancing patient and caregiver interests may be challenging. Perhaps the default should be to disclose, but not for patients for whom disclosure appears meaningless or even harmful (e.g. complete lack of insight, advanced dementia).

Organization of care and tasks of GPs

In a landscape of changing services for patients with dementia and of increasing collaboration with and task-delegation to nurses, the need arises to re-evaluate the role and position of the GP and of the practice nurse in the diagnosis and management of dementia³⁹. We see room for closer collaboration and better communication between GPs and specialists to diagnose dementia in the least burdensome way for patients, where possible by the GP and when required by the specialist. This also applies for the collaboration between GPs and

PNs with case managers, where there is also a need for a clearer division of tasks. The latter is complicated by the substantial heterogeneity in forms of case management between studies, and in the Netherlands also between different regions^{39,40}.

Future research and development

Case finding of MCI and dementia

To make future research into case finding more successful and possibly beneficial to patients and relatives, we recommend to focus case finding on older persons who are at increased risk of dementia and at increased risk of a missed diagnosis of dementia. To select such persons, medical record derivable risk factors may be used. Risk factors for dementia include diabetes, cardiovascular disease, emergency department visits and higher age^{8,41}. Risk factors for a missed dementia diagnosis include living alone and a low contact frequency and possibly also a higher age⁴². Selection based on such risk factors may be combined with GPs' clinical judgement of cognition^{11,43}. All persons to whom further evaluation of cognition is offered should receive diagnostic counselling. Notably, case finding interventions may have both positive (e.g. timely attention for the caregiver) and negative effects (e.g. misclassification, stigmatization). Future studies should make an effort to measure both the positive and negative effects of tested interventions.

Diagnostic assessment

There are many studies that assessed the diagnostic accuracy of a single test to confirm or reject the presence of dementia. However, since dementia is typically a diagnosis based on multiple sources of information (e.g. observation, proxy history, cognitive tests, physical examination), it would be much more informative if future diagnostic studies would assess the accuracy of multiple sources of information to establish a judgment⁴⁴. When the prior chance of dementia is considered low, a combination of cognitive tests in combination with an assessment of functioning may be superior to the commonly used MMSE^{35,45} to reject the presence of dementia^{27,28,46}.

Communication about a diagnosis of dementia and MCI

There is convincing evidence that communication training for formal and informal caregivers can positively affect quality of life and well being of persons with dementia, that it can

enhance caregivers' skills and competencies, and that it increases positive interactions⁴⁷. Strikingly, to our knowledge only very little research has been performed testing interventions aimed to improve physician communication, with no evidence of positive effects yet⁴⁸. The development and testing of new interventions to help physicians communicate with persons with dementia about topics including the diagnosis, future care and end of life care may benefit the patient, caregiver and possibly increase the commitment of providers⁴⁷. Assuming that GPs' reluctance to diagnose may be justified in some cases, it would be helpful to know more about GPs' arguments for non-disclosure in individual cases and about the characteristics of persons in whom GPs, possibly supported by relatives, regard disclosure inappropriate.

There is an urgent need for more guidance for GPs on communication about MCI. Limited evidence suggests that the information that physicians provide to persons with MCI shows large variation⁴⁹. There is a dearth of studies on patient preferences regarding disclosure of a diagnosis of MCI, but there are indications that it may be harmful⁵⁰. Since the concept of MCI was difficult even for clinicians, we expect less unequivocal findings than for disclosure of a diagnosis of dementia^{50,51}. Recommendations in primary care guidelines worldwide differ with regard to whether a diagnosis of MCI should be established and about further management. With the ageing of societies, GPs will face more people with (mild) cognitive impairment and will therefore need better guidance on how to support those people and their relatives^{35,52-54}. Future studies may investigate whether and how MCI patients want to be informed, and whether this is different for MCI subtypes with a high risk of conversion to dementia (i.e. multi-domain MCI) than for subtypes with a low risk of conversion⁵⁵⁻⁵⁷.

Overall conclusion

GPs' awareness of the presence of cognitive impairment among older persons in their practices is limited. This is probably a major cause of the underdiagnosis of particularly earlier stages of dementia in primary care. We tested an intervention to improve the recognition and diagnosis of MCI and dementia and subsequent care, but found no effects on the number of new diagnoses or on the mental health of older persons in whom GPs suspected cognitive impairment and their relatives. This may be due to the selected patient population, the low participation rate, and the implementation of the intervention. Based on the finding that most people without and with cognitive impairment want to be informed about a diagnosis of dementia we encourage open diagnostic counselling and proactive diagnostic assessment when patients present with possible cognitive impairment.

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