Dear Editor,

In their article Mitchell et al. (2008) presented a review about the long term risk of progression of mild cognitive impairment (MCI) to dementia. Across the included cohort studies, the mean annual conversion rate (ACR) to dementia was 4.2%, and a significant relationship was found between the ACR and the duration of the observation period. In studies of less than 5 years' duration the ACR varies from 10–15%, with a mean cumulative conversion rate of 31.4%. These figures correspond with preliminary results from the Descripa-study which found an ACR to dementia of 9.9% and a cumulative conversion rate (CCR) of 29.7% to dementia (ACR to AD: 8.6%; CCR to AD: 26.9%) in subjects with MCI from a memory clinic setting (Visser et al, 2008). Bearing in mind these data, and the high uncertainty about prognosis, it is becoming increasingly relevant to know what is currently told to patients after MCI has been diagnosed.

Additionally, we should define best practice in informing the patient and caregiver in case of MCI. Looking from the professionals’ point of view, T Mitchell et al.(2008) reported that most clinicians found it important to distinguish MCI from normal cognition and AD, and indicated that they share a diagnosis of MCI with both the patients and their proxies (84% and 87% in N=163, respectively). To describe current practice, we studied diagnostic disclosure in patients with MCI from the Descripa study in an optional questionnaire added to the main data collection (N=124). We found that the terms used to inform the patient about the diagnosis of MCI varied considerably. We also found that almost 80% of the patients were informed about their prognosis of which 64% received the information that their memory problems will be ‘probably progressive’. It is important to realize that in this study clinicians did not report if and how they specified this information in terms of expected memory or behavior problems, neither did they give an
indication for the time period in which this progression would probably occur. When there was a suspicion of pre-dementia AD (77 cases:62%), in 76% of the cases this was told to the patient.

Our conclusions are:
1. Clinicians tell patients that MCI is progressive more often than is justified by the observed conversion rate from the Mitchell meta analysis and the Descripa study. This may mean that a lot of patients receive a wrong prognosis, which may lead to unjustified worries.
2. The findings also indicate that clinicians have different disclosure practices. MCI as a diagnostic label seems difficult for clinicians to unequivocally explain in the disclosure meeting.

What should be told?
In a qualitative study on diagnostic disclosure in dementia (N=18 dyads of patient and caregiver) we noted that most patients and carers reported that they had experienced the disclosure of the diagnosis of dementia as a confirmation of their assumptions without being stressful (Derksen et al, 2006). However, this may not apply to subjects with MCI. Joosten et al.(2008) question the benefits of MCI as a diagnostic label, since it tends to prolong the patient’s uncertainty. If we want to take away this uncertainty it is important, in future research, to find the predictors for high probability of conversion from MCI to dementia. When it is possible to give a prognosis of ‘probably progressive’ MCI, patients need specified information about their condition and advice on how to cope with their memory problems. The disclosure of the diagnosis as ‘MCI’ as such, how informative it may seem, is too often highly troubling for both patient and caregiver.

References

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