

Perspective

# Diagnostic dilemmas in Alzheimer's disease: Room for shared decision making

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## Abstract

The launch of the NIA-AA research criteria for Alzheimer's disease (AD) diagnosis illustrates the large advances that have been made in the field of AD diagnosis. These new possibilities however also introduce new dilemmas into the consulting room, and this provides room for shared decision making (SDM). SDM refers to clinicians and patients (and/or their caregivers) working together to decide which care plan best fits individual patients and their lives, when there is more than one reasonable option. Here, we describe how SDM in the diagnosis of AD promotes patient-centered care, as it helps to adapt the diagnostic process to the patients' values and preferences. We provide an outline for a research agenda, as SDM in the diagnosis of dementia should be studied intensively incorporating the views of both patients and caregivers.

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## Keywords:

Shared decision making; Communication; Mild cognitive impairment; Alzheimer; Diagnostic testing

The launch of the NIA-AA research criteria for the Alzheimer's disease (AD) diagnosis illustrates the large advances that have been made in the field of AD diagnosis [1]. The NIA-AA criteria acknowledge that AD starts well before the stage of dementia; hence, in addition to the criteria for dementia due to AD, there is a separate set of criteria for MCI due to AD [2]. Both dementia and MCI criteria allow the use of biomarkers to provide evidence for the likelihood that the clinical syndrome can be attributed to underlying Alzheimer pathology. These new possibilities introduce new dilemmas into the consulting room: Which test to use in which patient? In which order? How to deal with conflicting test results, or test results that are borderline

(ab)normal? How to interpret abnormal test results in patients who are not yet demented? In view of all these dilemmas, the question arises how to discuss all these with the patient. For example, (when) do patients and their caregivers want to initiate testing, and what are their motivations to consider testing? Diagnosis of AD can be difficult, especially in the predementia stage, and uncertainty is inherently implicated in the outcome of diagnostic testing.

Shared decision making (SDM) refers to clinicians and patients (and/or their caregivers) working together to decide which care plan best fits individual patients and their lives, when there is more than one reasonable option [3]. The concept of SDM emerged when advances in medicine led to a shift from acute to chronic care (such as in diabetes mellitus and chronic heart disease), implying that sickness may no longer be a temporary status, but a state of being, which comes with new dilemmas and choices to be made [4,5]. In addition, SDM was an answer to the increasing number of reasonable options to address a patient's situation, such as

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in cancer where in a given situation one might operate, start chemo, or decide not to initiate treatment at all [4,5]. SDM is based on the idea that patients' informed preferences should be a component of professional actions [6].

In SDM, both clinician and patient are considered to be experts: clinicians are medical experts on the disease and the clinical evidence, and patients are experts on how they experience their illness and on what matters (most) to them in their personal lives [7,8]. As such, SDM contributes to patient autonomy and hence, to personalized care. Key elements of SDM include the following: (1) clarify the patient's situation, (2) acknowledge that there is more than one option available to address this situation (choice awareness), (3) discuss the pros and cons of the different options, (4) discuss what the patient values about these options, and (5) make the decision [3,9,10].

Numerous studies on SDM have shown positive effects on patient-reported outcomes. SDM has been associated with improved satisfaction and self-perceived health of patients with diverse diseases, such as cardiovascular disease, cancer, depression, or diabetes [11]. In primary care settings, patients perceived more control over their medical situations [11]. In a few studies, SDM has improved treatment adherence, for example, in asthma or depression [11]. Furthermore, SDM may reduce practice variation that cannot be explained by illness severity or patient preferences [12]. Use of SDM in clinical practice could lead ultimately to a reduction in health care costs, although this is not its primary goal [13,14].

Considering the large body of evidence on the value of SDM in other disease areas, dementia lags behind. Yet, dementia patients—especially those in earlier stages—and their caregivers prefer to be involved in decisions about health and care [15,16]. The few available studies have focused on patients with an established diagnosis of dementia, facing decisions about everyday care, medical treatment, or long-term care placement [15,16]. This is similar to other disease areas, where there has been a strong focus on treatment and management decisions, neglecting decisions around diagnostic care. Particularly in the diagnostic stage, however, there is ample room for shared decision making. The development of novel diagnostic tests for AD has resulted in an increasing number of available options, including the option not to test. Engaging in an SDM process and ensuring that decisions about testing incorporate patient's values and preferences contribute to patient-centered care [17].

In this issue, we report on the first steps in evaluating clinician-patient communication and SDM in the diagnosis of dementia, by assessing views and experiences of clinicians, patients, and caregivers concerning diagnostic decisions [18,19]. We conducted focus groups and a survey and found that clinicians prefer an SDM approach and feel they involve patients in decision making in routine care. Yet, our studies suggest that clinicians' efforts to involve patients is limited to providing patients with information, only one of the elements of SDM [3,9,10]. Patients and caregivers on

the other hand said they felt involved in the decision to initiate testing, while decisions about which specific tests to use were made by clinicians. In addition, although clinicians attempted to inform patients and their caregivers about the diagnostic process, the test results, and the diagnosis, patients and caregivers still missed information on these topics. Our studies are merely first steps to structurally assess SDM in the diagnosis of dementia, and results should be seen as agenda setting, rather than hypothesis testing.

This was a Dutch study, but results on clinician-patient communication were largely comparable to the few studies on this topic that have been performed before. For example, clinicians' views on the use of the term MCI and other diagnostic labels and whether they convey a diagnosis were in line with former studies [20]. Our studies add to these earlier studies the topic of SDM. As our findings are quite in line with earlier studies on SDM in other disease areas, we are confident that our results will be generalizable across other Western countries. Previous research has shown that clinicians, regardless of specialty, indicate that they prefer to involve patients in decision making. Observational studies, however, have shown that this involvement is generally rather limited [21]. Therefore, to empirically investigate SDM in dementia diagnosis, we are currently performing a multicenter audiotape study, to observe clinician-patient communication before and after diagnostic testing. The results of this study can shed light on those aspects of communication and SDM that would particularly benefit from support, for example, by developing e-learning and (online) tools. Furthermore, important next steps include conducting larger, multinational studies to assess generalizability and possible cultural differences.

There are a number of aspects that deserve specific attention in communication and SDM studies of AD. First, the primary symptom of AD is cognitive decline, which impacts communication and disease insight. As the disease progresses, patients will have a changing role in their own disease process, which highlights the need to pay deliberate attention to the role of the caregiver, as well as to the communication between caregiver and patient [22,23]. Second, specific attention should be paid to the interpretation and communication of test results, especially when patients are not yet demented (i.e., MCI, subjective cognitive decline) and interpretation is not straightforward. Of note, true longitudinal data on the implication of biomarker results for long-term prognosis are not yet available. Finally, the current lack of disease-modifying therapies for AD or any other type of dementia complicates decisions and the impact of receiving abnormal biomarkers results, particularly if there is not yet a syndrome of dementia. SDM studies should focus on patients' and caregivers' expectations of the diagnosis, what information they are looking for, and how they deal with uncertainty.

Of note, among the largest hurdles in developing treatments is finding enough participants for research [24]. Clinician-patient conversation on trial participation should be improved and such participation should be offered to

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