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Featured Article

Clinicians' views on conversations and shared decision making in diagnostic testing for Alzheimer's disease: The ABIDE project

Marleen Kunneman[a], Ellen M. A. Smets[a], Femke H. Bouwman[b], Niki S. M. Schoonenboom[c], Marissa D. Zwan[b], Ruth Pel-Littel[d], Wiesje M. van der Flier[b,e,*]

[a]Department of Medical Psychology, Academic Medical Center, Amsterdam, The Netherlands
[b]Alzheimer Center and Department of Neurology, VU University Medical Center and Amsterdam Neuroscience, Amsterdam, The Netherlands
[c]Department of Neurology, Spaarne Gasthuis, Haarlem, The Netherlands
[d]Vilans Centre of Expertise for Long-Term Care, Utrecht, The Netherlands
[e]Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

Abstract

Introduction: This study explores clinicians' views on and experiences with when, how, and by whom decisions about diagnostic testing for Alzheimer's disease are made and how test results are discussed with patients.

Methods: Following a preparatory focus group with 13 neurologists and geriatricians, we disseminated an online questionnaire among 200 memory clinic clinicians.

Results: Respondents were 95 neurologists and geriatricians (response rate 47.5%). Clinicians (74%) indicated that decisions about testing are made before the first encounter, yet they favored a shared decision-making approach. Patient involvement seems limited to receiving information. Clinicians with less tolerance for uncertainty preferred a bigger say in decisions ($P < .05$). Clinicians indicated to always communicate the diagnosis (94%), results of different tests (88%–96%), and risk of developing dementia (66%).

Discussion: Clinicians favor patient involvement in deciding about diagnostic testing, but conversations about decisions and test results can be improved and supported.

Keywords: Shared decision making; Communication; Dementia; Alzheimer; Diagnostic testing

1. Introduction

The NIA-AA criteria state that diagnostic tests for Alzheimer's disease (AD), such as MRI and biomarkers in cerebrospinal fluid (CSF), should be used "when available and deemed appropriate by the clinician" [1]. Information on when to use which test or how to involve patients and their families in this decision is not specified, leaving room for broad practice variation in diagnostic testing. At the same time, there has been a shift toward earlier diagnosis of AD, which has led to mild cognitive impairment (MCI) due to AD being regarded as a formal diagnosis in the AD spectrum [2]. A diagnosis of AD or MCI may have great social, emotional, and practical implications for patients and their families, whereas at present, there is still no cure available. On the other hand, an early diagnosis could have the advantage for patients and their families to be more involved in management decisions and planning of care and help them prepare for the future [3]. Moreover, it may meet their needs to minimize uncertainty about the nature of the patient's symptoms and what may lay ahead [4]. However, test results do not always offer patients and their families the certainty or reassurance they were seeking for [5]. Results of different

*Corresponding author. Tel: +31 (0)20 4440816; Fax: +31 (0) 20 4440715.
E-mail address: wm.vdflier@vumc.nl

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diagnostic tests may be equivocal or conflicting, making it challenging for clinicians to interpret these results and discuss them with the patient, especially in the context of MCI [6].

All these issues contribute to the diagnostic challenges in AD, that is, how to decide about diagnostic testing, and how to communicate test results to patients and caregivers. As it is likely that patients will weigh the advantages and disadvantages of testing differently, clinicians and patients can engage in a shared decision-making (SDM) process to ensure patients' views and preferences are considered in deciding about testing [7,8]. SDM has been studied extensively in other clinical contexts [9], but only a few studies are available in the context of MCI and dementia. These studies show that although both patients and their caregivers prefer to be actively involved in decisions regarding their care [10–12], especially, patients are involved to a limited extent only [13,14]. However, these previous studies involved patients with an established diagnosis of MCI or dementia and concerned SDM in the context of decisions about subsequent disease, symptom, or care management.

As a first step in studying SDM in the diagnostic care of AD, the aim of this study was to explore clinicians' views on and experiences with (1) when and how to decide about diagnostic testing for AD, (2) the role of the patient and clinician(s) involved in this decision, and (3) which test results to communicate to patients and how. Finally, we assessed whether clinicians' views and experiences were associated with their characteristics (sociodemographic, work-related, and tolerance for uncertainty in care).

2. Methods

2.1. Design

This study was conducted as part of a larger project on the (cost)effectiveness of diagnostic tests for AD and MCI [15]. To explore emerging issues as a preparation to a survey, we first conducted an in-person focus group with Dutch neurologists and geriatricians working in a memory clinic. We then disseminated an online survey among >200 neurologists and geriatricians working at one of the 120 Dutch (local) memory clinics.

2.2. Focus group

Neurologists and geriatricians who registered for a 1-day national conference on dementia were invited to participate in a focus group. During the 2-hour focus group, which was led by a psychologist experienced in conducting focus groups (E.M.A.S.), we discussed clinicians' dilemmas regarding diagnostic testing for AD (e.g., how and when it is decided to initiate which diagnostic tests), the role of the patient in this decision, and which test results or diagnostic labels are communicated to the patient and how. The audio recording of the focus group discussion was transcribed verbatim and analyzed using MaxQDA software.

2.3. Survey

Based on the literature and the themes that emerged from the focus group, we developed an online survey to assess clinicians' views nationwide. The patients' caregivers have an important role in this setting, but given that SDM in diagnostic care is still novel, we decided to present patients and caregivers as one party in this survey. At the start of the survey, we explicitly stated to read "patients and caregivers" whenever we spoke of "patients." The survey contained the following scales and items to address our aims:

- Clinicians' sociodemographic and work-related characteristics, such as age, gender, specialty (neurology or geriatrics), type of hospital (academic, nonacademic teaching hospital, nonteaching hospital, or other), and level of experience (years since specialization and number of new patients per month).
- The Physicians' Reaction to Uncertainty Scale to assess clinicians' affective reactions to uncertainty in health care. This scale consists of items that address the emotional reactions and concerns engendered in clinicians who face clinical situations that are not easily resolved and clinicians' behavior to cope with those emotions and concerns [16]. We used the subscales "Anxiety due to uncertainty" and "Reluctance to disclose uncertainty to patients (excluding one item on the use of treatments)" (six-point Likert scale strongly disagree to strongly agree). Scores were calculated by summing the responses to the items of the two subscales, with a higher score meaning less tolerance for uncertainty (score range 9–54).

Scales and items that are related to deciding about testing:

- Clinicians' perceived reason for the prediagnostic clinician-patient encounter (see Table 1, make a top three) [17].
- The extent to which clinicians perceive that the decision about whether to initiate testing has been made before the prediagnostic clinician-patient encounter (six-point Likert scale not at all to very much); who has the biggest say in this decision (select one from treating specialist, multidisciplinary team, general practitioner, and patient/caregiver); and which factors are important in this decision (see Fig. 1, select one or more).
- The Control Preferences Scale [18,19] to assess clinicians' preferred role in deciding about whether to (1) initiate diagnostic testing, (2) use imaging techniques, and (3) perform lumbar puncture for CSF biomarkers. Answer categories ranged from (1) the patient makes the decision alone, through (2) the