

Featured Article

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

Marleen Kunneman^a, Ruth Pel-Littel^b, Femke H. Bouwman^c, Freek Gillissen^c,
Niki S. M. Schoonenboom^d, Jules J. Claus^e, Wiesje M. van der Flier^{c,f,*}, Ellen M. A. Smets^a

^aDepartment of Medical Psychology, Academic Medical Center, Amsterdam, The Netherlands

^bVilans Centre of Expertise for Long-Term Care, Utrecht, The Netherlands

^cAlzheimer Center and Department of Neurology, VU University Medical Center and Amsterdam Neuroscience, Amsterdam, The Netherlands

^dDepartment of Neurology, Spaarne Gasthuis, Haarlem, The Netherlands

^eDepartment of Neurology, Tergooi Hospital, Hilversum, The Netherlands

^fDepartment of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

Abstract

Introduction: This study aims to assess patients' and caregivers' views on and experiences with (1) decisions about diagnostic testing for Alzheimer's disease (AD) and (2) receiving test results.

Methods: We conducted separate focus groups with patients from three hospitals who underwent diagnostic testing for AD ($N = 11$) and their caregivers ($N = 11$). Audio recordings were transcribed verbatim and analyzed using MaxQDA.

Results: Patients and caregivers preferred and perceived active involvement in decision making, but the decision to initiate diagnostic testing seems to be made before the clinician-patient encounter. Patients and caregivers indicate that decisions are driven by a strong need to explain the patient's symptoms. They missed information on why different diagnostic tests were used, what the results of these tests were, and to what extent these results were (ab)normal.

Discussion: The decision-making process around diagnostic testing for AD and the information provision before and after diagnostic testing could be improved.

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Keywords:

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

1. Introduction

In recent years, increased scientific and clinical knowledge and improvements in diagnostic care have caused a shift toward earlier diagnosis of Alzheimer's disease (AD) [1,2]. Such timely diagnosis could allow patients and their families to be more involved in their care and in management decisions and planning [3]. However, deciding to undergo diagnostic testing can be difficult, especially in

early stages when normal aging is transitioning into early dementia. On the one hand, patients may believe that (early) diagnostic testing could decrease their uncertainty around the nature of their symptoms and around their future [3,4]. On the other hand, patients may be inclined to delay diagnostic testing, possibly influenced by their perceived (limited) severity of symptoms or their anxiety for bad news. After diagnostic testing, receiving test results may not always offer patients and their caregivers the certainty or reassurance they were looking for, especially when results are equivocal or conflicting or when patients are diagnosed with mild cognitive impairment (MCI), as the implication of biomarker results for long-term prognosis is still unclear. These considerations and uncertainties, and the

*Corresponding author. Tel.: +31 (0)20 4440816; Fax: +31 (0) 20 4440715.

E-mail address: wm.vdflier@vumc.nl

possibility for individual patients to weigh these differently, make the decision whether to initiate diagnostic testing highly suitable for a process of shared decision making (SDM).

In SDM, clinicians and patients engage in a conversation to make decisions about care that best fit the individual patient and his or her situation [5,6]. In the area of MCI or dementia care, only a few studies on SDM are available, which all focus on decisions on advanced care management in patients with an established diagnosis [7,8]. These studies showed that although both patients and their caregivers wish to be involved in medical decision making, especially patients are involved to a limited extent only. In a companion study, we show that most neurologists and geriatricians favor an SDM approach and believe they actively involve patients in diagnostic decisions [9]. In the same study, almost all clinicians indicated they discuss the diagnosis and the test results that led to this diagnosis. Yet, we do not know how patients and their caregivers experience their involvement in deciding about diagnostic testing, nor how they experience the disclosure of test results.

The aims of this study were to further study SDM in the context of diagnostic care of AD, by exploring patients' and informal caregivers' views on and experiences with (1) decisions about diagnostic testing for AD and (2) receiving test results.

2. Methods

2.1. Design

This study was conducted as part of ABIDE, an ongoing multicenter project on diagnostic testing for AD and MCI [10]. We conducted in-person focus groups with patients and their informal caregivers. Participants provided written informed consent before the focus group meeting and completed a short questionnaire in the following days. The Medical Ethics Committee of the Academic Medical Center Amsterdam approved the study.

2.2. Sample and recruitment

Consecutive patients who underwent diagnostic testing—irrespectively of diagnosis—in an academic (VU University Medical Center, Amsterdam) or nonacademic hospital (Tergooi Hospital, Blaricum; Spaarne Hospital, Haarlem) and their informal caregiver were asked for participation. To minimize recall difficulties, focus groups were scheduled within 8 weeks of patients receiving test results. Patients with poor comprehension of the Dutch language or patients who were not able to provide informed consent were not asked for participation.

2.3. Focus groups

Focus groups for patients and caregivers were held simultaneously but separately as we expected different views and

experiences [11]. All focus groups were organized at the memory clinic which patients had visited before and were held during the evening, allowing those with daytime obligations to attend. Two researchers (M.K. and E.M.A.S.) and a nurse consultant (F.G.) facilitated the focus group discussions. Focus groups were planned to last 70 minutes, including a 10-minute break, and were audiotaped. The first part of the interview protocol concerned topics on deciding about diagnostic testing, such as (1) preferred and perceived involvement in decisions; (2) timing of decision making; and (3) reasons to initiate testing. The second part concerned topics on discussing test results, such as (1) receiving diagnosis and/or test results; (2) receiving information on prognosis and chances of developing AD; and (3) understanding of test results and implication of these results for daily life.

2.4. Questionnaire

To aid interpretation of findings, patients and caregivers were asked to fill in a short questionnaire on their characteristics, with the following scales and items:

- Sociodemographic characteristics, such as age, gender, educational level, living situation (patients only), and relation to patient (caregivers only).
- Patient's disease characteristics, such as time since onset of symptoms, who is most concerned about the patient's symptoms (patient, caregiver(s), other doctor such as the general practitioner, or someone else), the patient's diagnosis (open question), and whether their consultation was a second opinion (caregivers only, no/yes).
- A single item on their need for information about the patient's disease and treatment (11-point Likert scale 0: I want to know as little as possible to 10: I want to know as much as possible).
- The Control Preferences Scale [12,13] to assess their preferred role in deciding about care. Answer categories ranged from (1) (My significant other and) I make the decision alone, through (2) (My significant other and) I make the decision after considering the doctor's opinion, (3) (My significant other and) I make the decision together with the doctor, (4) The doctor makes the decision after considering my (and my significant other's) opinion, to (5) The doctor makes the decision alone.

2.5. Data analysis

Audio recordings of the group meetings were transcribed verbatim. A content analysis was performed on the transcripts, using MaxQDA software for qualitative research [14]. All transcripts were independently coded by two researchers (M.K. and R.P.-L.) with respectively a background in medical decision making and elderly care. Discrepancies were discussed and solved in consensus. Coding was done both deductively and inductively, starting with predefined

Table 1
 Characteristics of participating patients ($N = 11$) and caregivers ($N = 11$)

Participant ID	Age	Gender	Educational level [†]	Relationship to patient	Living situation (patients)	Most concerned about symptoms	Time since onset symptoms	Second opinion (caregiver)	Self-report diagnosis (patient)	Information need (0–10 scale)	CPS score (1–5 scale) [‡]	Diagnostic tests used [§]
P11	61	M	Intermediate		With partner	Caregiver(s)	5 months		I don't know	5	4	MMSE, CAMCOG, npsy, MRI, CSF
C11/1	62	F	Intermediate	Partner		Caregiver(s)	1–2 years	No	FTD	10	3	
C11/2	39	F	Intermediate	Daughter		Caregiver(s)	2 years	No	FTD	10	4	
P12	69	F	Intermediate		With partner		4 years		No diagnosis	10	3	MMSE, CAMCOG, npsy, MRI, PET
C12	68	M	Intermediate	Partner		Caregiver(s)	4 years	Yes	Degenerating brain	10	3	
P13	65	M	Intermediate		With partner	Patient	3.5 years		MCI/early AD	10	3	MMSE, CAMCOG, npsy, MRI, PET
C13	60	F	Intermediate	Partner		Patient	3.5 years	Yes	Early AD/MCI	10	3	
P14	60	M	High		With partner	Caregiver(s)	2 years		FTD	10	3	MMSE, CAMCOG, npsy
C14*		F		Partner								
P15	65	F	High		Alone	Caregiver(s)	1 year		AD	10	3	MMSE, CAMCOG, npsy, MRI, PET
C15	71	M	High	Friend/neighbor		Caregiver(s)	3 years	Yes	Early AD	10	2	
P21	78	F	Low		With partner	Caregiver(s)	1 year		AD	5	2	MMSE, CAMCOG, npsy
C21	79	M	Intermediate	Partner		Caregiver(s)	1 year	No	AD	8	2	
P22	68	M	High		With partner	Caregiver(s)	4 years		Early AD	10	3	MMSE, CAMCOG, npsy, MRI, CSF
C22	57	F	High	Partner		Caregiver(s)	4 years	No	Early AD	10	3	
P23	76	M	High		With partner	Caregiver(s)	1 year		Early AD	9	3	MMSE, CAMCOG, npsy, MRI, CSF
C23	75	F	Intermediate	Partner		Caregiver(s) and patient	1 year	No	AD	10	3	
P31	73	M	High		With partner	Caregiver(s)	5 years		No reason to be concerned, no dementia	5	1	MMSE, GDS, CAMCOG, MRI
P32	67	M	Low		With partner	Caregiver(s) and patient	10 years		Memory problems	10	3	MMSE, CAMCOG
C32	63	F	Intermediate	Partner		Daughter and friend	1 year	No	Memory problems	10	3	
P33	80	M	Intermediate		With partner	Caregiver(s)	6 months		AD	1	3	MMSE, CAMCOG, MRI
C33	73	F	Intermediate	Partner		Caregiver(s)	1 year	No	Early AD	10	3	

Abbreviations: CPS, Control Preferences Scale; MCI, mild cognitive impairment; AD, Alzheimer's disease; FTD, frontotemporal dementia; MMSE, Mini Mental State Examination; CAMCOG, Cambridge Cognitive Examination; npsy, neuropsychological investigation; MRI, magnetic resonance imaging; CSF, cerebrospinal fluid; PET, positron emission tomography; GDS, geriatric depression scale.

*Participant did not return questionnaire.

[†]Educational levels included low = completed no/primary school, intermediate = completed lower general secondary education/vocational training, or high = completed pre-university education/high vocational training/university.

[‡]CPS scale ranges from (1) (My significant other and) I make the decision alone, through (2) (My significant other and) I make the decision after considering the doctor's opinion, (3) (My significant other and) I make the decision together with the doctor, (4) The doctor makes the decision after considering my (and my significant other's) opinion, to (5) The doctor makes the decision alone.

[§]Data collected from patient's medical record.

Table 2
Patients' and caregivers' expectations regarding testing, test results, and care

P12: Since [partner] has been at home [retired], he thinks I have Alzheimer's.

P15: I thought it might still be okay for a year or so, but perhaps it will be useful if I already [get tested].

P33: I was convinced I didn't have Alzheimer's, and my wife had her doubts.

P22: I'm not afraid of reality (...) so if I hear that something's wrong, I'm glad to know about it and that something can be done about it.

C33: then I said to my husband, why not have it checked out, then we will know for sure. And if you do have it, at least you can start taking medication quickly. (...) And then it turned out he did have it. I was not expecting that.

P14: We decided with the company doctor at work (...) to have it checked out and possibly cured.

codes based on outcomes of our earlier study on clinicians' views [9], and allowing new codes to flow from the data. Whenever changes in (descriptions of) codes were introduced, all previously coded transcripts were checked again for recoding. Descriptive statistics were used to report patients' and caregivers' characteristics.

3. Results

3.1. Participants

We conducted three focus groups for patients and three for caregivers, after which we had a first inventory of participants' views and were confident that data saturation was reached. We included 11 patients (mean age 69 ± 6.6 , 3 females) and 11 caregivers (mean age 64 ± 12.1 , 8 females).

The questionnaire revealed that both patients (median = 10, range 1–10) and caregivers (median = 10, range 8–10) had a high need for information on the patient's disease and treatment. Most patients and caregivers preferred a shared approach in deciding about testing. Mean preferred involvement (Control Preferences Scale) scores were about the same for patients (median = 3, range 1–4) and caregivers (median = 3, range 2–4). Most patients and caregivers indicated that it was the caregiver who was most concerned about the patient's symptoms. Participants' characteristics are presented in Table 1.

Content analysis showed that participants' views regarding decision making could be grouped into two domains: (1) expectations regarding testing, test results, and care and (2) decisions about diagnostic testing and perceived roles. Views on receiving test results could also be grouped into two domains: (1) receiving diagnosis and/or test results and (2) implications of diagnosis and/or test results. In addition, we composed one category with participants' other relevant experiences of communication and care around diagnostic testing.

3.2. Expectations regarding testing, test results, and care

Most patients and caregivers indicated that before diagnostic testing, they expected the patient's symptoms to be

due to AD or another type of dementia. They reported a strong need to explain or confirm what was causing these symptoms. Some patients, but especially caregivers, believed that receiving an early diagnosis would be beneficial. Before testing, they believed that a diagnosis could reduce uncertainty on what caused the patient's symptoms and help receive the necessary care and start with medications or "cures" as soon as possible (see Table 2 for quotes).

3.3. Decisions about diagnostic testing and perceived roles

Because of the strong need to explain the symptoms, most patients and caregivers indicated to prefer diagnostic testing (Table 3). Possible disadvantages of diagnostic testing were not mentioned during the focus groups, although some patients were not convinced of the necessity of testing (Table 3). Most, but not all, patients perceived having an active role in the decision to undergo testing. Some said this was at their own initiative, and others indicated strong encouragements or even pressure from family members (Table 3). In addition, the general practitioner seemed to have an important role in initiating diagnostic testing, either by raising the topic of testing, or by confirming the necessity of testing (Table 3). Participants mentioned several factors that influenced the decision to initiate diagnostic testing, mainly a family history of dementia and (young) age. One patient (P11) recently lost his job due to his symptoms, and his two caregivers feared that he would not be able to find new employment. The caregivers indicated that they had financial motives to receive a diagnosis, to ensure a social security income (Table 3).

Regarding the decision(s) about which tests to use, patients and caregivers felt these were mostly made by the clinician and without their own involvement. Some indicated this was a reason for concern, as they wondered whether they received the best care available, and others found it comforting that clinicians made these decisions (Table 3).

3.4. Receiving diagnosis and/or test results

All participants but one patient (P11) indicated receiving a diagnosis. Of note, this is the patient who recently lost his job due to his symptoms and visited his general practitioner and the memory clinic because his daughter scheduled an appointment. He indicated it was unclear to him why these visits were scheduled. Even for those patients and caregivers who expected the diagnosis, receiving the diagnosis reportedly made them impervious to all the other information (Table 4). To most participants, it was unclear which specific test results led to the diagnosis, which made some feel uncertain and left in the dark (Table 4).

Especially, caregivers indicated a strong need for information on the disease stage, that is, apart from receiving information on whether the patient had dementia (yes/no), they had a strong wish for information on the extent to which

Table 3
Patients' and caregivers' views regarding decision making

Preferences regarding initiation of diagnostic testing
 C12: I made the choice myself, without discussing it, because it was impossible to discuss things at that time (...)
 P15: Yes, absolutely [own choice] (...) There was no doubt, I thought I now need to [get tested]...

Possible (dis)advantages of diagnostic testing
 C32: I just thought, there's no harm in finding out.
 [Interviewer: did you also consider not being tested, perhaps because you really didn't want to know?] P22: no, no. P21: I actually did. But my husband wanted to (...) I thought I'm actually fine, aren't I?

Perceived role in decision making
 P11: It was my daughter who signed me up [to go to the doctor], it's as simple as that and so I did it (...) [interviewer: did she have a reason?] I don't think so, yes I do forget things, but otherwise no.
 C21: My daughter is the guilty one and she is also getting the blame, of course. (...) She noticed it, I also noticed it but said nothing. Not even to my daughter, actually.

Role of general practitioner
 P23: Our GP said (...) I would advise you to do it, you are a healthy guy and you can never be too early if there is something special on the market that will reduce the problems or get rid of them.
 C33: I believe that we didn't even have an initial appointment because the GP said that tests would need to be done.

Factors that influenced the decision
 P15: it runs in the family, and that is another reason why I decided relatively quickly to do something.
 C22: [lumbar puncture] was suggested because they felt that [patient] was still relatively young. They do not do that with everyone.
 C11.2: Because he was actually fired on the spot, you need to apply for unemployment benefits, but I wanted it to be sickness benefits, because I thought: a new job is out of the question. C11.1: it has financial consequences.

Decisions about which diagnostic tests to use
 [interviewer: did you know in advance what tests would be done?] C23: no, not the type of tests. C21: no. (...) I don't know the exact details of what happened with my wife.
 C22: [about psychological tests and MRI] I thought that they were the only options for testing. (...) I'm really quite amazed that everything is so different. (...) Why does everyone get a different type of test?
 C12: That's strange, we actually get both [MRI and PET]. C13: I also find that strange, we were not assigned to that. (...) I would like to have that, I didn't have a CT scan.
 [interviewer: was it clear why those tests and that MRI were done and what they were trying to find out?] C32: no, not to me, but I don't think that's necessary.
 [interviewer: did you feel overwhelmed by all those tests?] P12: no, you don't have a choice, you don't have a choice. P15: You just have to take it all as it comes. (...) no doubt they will do what is useful, so I just went into it blind and full of trust.

patients were demented. According to the participants, some clinicians attempted to provide feedback on the extent of cognitive decline, for example, by showing the cerebral atrophy on a scan (Table 4). There was a tendency among participants to believe that some diagnostic tests, that is, lumbar puncture for cerebrospinal fluid biomarkers, provided more certainty on the diagnosis than other tests (Table 4).

3.5. Implications of diagnosis and/or test results

Some patients and caregivers indicated that the label of (early) dementia helped in dealing with the patient's symptoms. Others reported having difficulties coping with that label, as it felt like an "incurable curse." Looking back, some caregivers questioned whether they did the right thing by initiating diagnostic testing, and others indicated that receiving a diagnosis brought them comfort (Table 5). Both patients and caregivers felt a need for more information on the prognosis of the disease and of possible treatments or lifestyle changes to stabilize or undo the patient's cognitive decline (Table 5).

3.6. Other relevant experiences of communication and care

During the focus groups, some additional unexpected topics were addressed that are worth noting. First, caregivers

indicated that their prominent role in the patient's care and decisions about care is burdensome to them. Some caregivers indicated to avoid (eye)contact with the clinician during consultations or to downsize symptoms as a gesture to support their loved one (Table 6). Second, some caregivers indicated that in general, their relationship with the patient was changing from one that used to be based on love and equality to one that is caring and dependent. Instead of being one team, they had different views and goals (Table 6). Finally, many participants reported that the limited time with the clinician seemed to hinder their conversations. Some expressed to value having a consultation with a psychologist or nurse, either directly after their encounter with the clinician or after a few days (Table 6).

4. Discussion

Our study showed that patients and their caregivers prefer to be actively involved in decisions around diagnostic testing for AD, but that they often miss crucial information on pros and cons of testing to participate in an SDM process or to understand the results and consequences of diagnostic testing.

Patients and especially caregivers seemed to have a strong preference to initiate diagnostic testing for AD—even before their consultations with the clinician—driven by the need to find an explanation for the patient's

Table 4
Patients' and caregivers' views regarding receiving diagnosis and/or test results

Receiving a diagnosis

C11.2: eventually, you come for the results, but really it just confirms the (C11.1: diagnosis).

P15: well, it's the early stages of Alzheimer's (...) it didn't seem to have much impression on me except for the news, the confirmation of what I was afraid of. Perhaps it blocked all the information processing, it seems to me.

Which test results led to diagnosis

C21: I didn't see anything, I only dealt with [specialist] who is actually quite direct, just says what the matter is and that is very in your face. (...) I don't have any test results or anything.

P13: A relatively short conversation with a clear opinion, you have the early stages of Alzheimer's. But very little about the results of the tests, how well or badly you did (...) When we got home, we both had the feeling that we were actually missing an awful lot of information.

C14: [patient] would like to know what he scores (...) because then someone says (...) I will say three words apple key table, now repeat them. [patient] repeats them, but only remembers two. (...) [patient] has often said, because I can't remember three words, I'm not allowed to drive a car.

Need for information on test results

C11.2: it would be great, if only on a scale of 1 to 10, he is somewhere around there. (...) I would very much like to know whether my father is in the early stages, in the middle, or at the end. (...)

P14: He [doctor] called it a certain kind of dementia, I can't remember offhand what it was, it was something really unusual (...) I would like to talk to him again to get more information and details. (...) What I could and could not do and whether he can give me a score.

P31: I find that a bit silly: "look at that," and I look and see a head on a screen, but you have no frame of reference, you don't know what you are really seeing.

Certainty provided by different diagnostic tests

P13: It's distressing to have all these tests that show you that you can only remember three when I should actually remember seven. So yes, you know it. But you would still like to have that confirmation (...) what is the result from the lumbar puncture.

C22: [that lumbar puncture was] good, because it gives you certainty that it really is Alzheimer's.

symptoms. In addition, they seemed to mainly focus on the potential benefits of (early) testing, namely to reduce uncertainty or to start treatment. Possible drawbacks were only considered by some post hoc, that is, after receiving an impactful diagnosis of MCI, AD, or other type of dementia. Currently, it seems that even before the clinician can share relevant information about the options available, and even before the patient can share relevant information about their personal context and preferences, all seem to assume that initiating diagnostic testing is the "right" decision. The referral by the general practitioner to a memory clinic may be an important factor for this assumption, as referral in itself may suggest that diagnostic testing, at this time, is the right thing to do. This diminishes possible awareness of choice between options and pre-empts the need for an SDM conversation at the memory clinic. It is however also likely that the preference for testing is formed even before seeking care and contacting the general practitioner. This deserves attention in future research.

In our earlier study, the great majority of clinicians indicated they always discuss the diagnosis and the test results with the patient [9]. Patients and caregivers indeed indicated they received a diagnosis, but they felt that information on how clinicians came to this diagnosis, and to what degree test results were deviant, was lacking. In addition, they felt left in the dark after receiving the diagnostic label, uncertain of what the prognosis is, how symptoms will progress over time, and what possible disease management strategies are. Our findings suggest that, when information on these topics is shared, this is likely not done in a manner that helps patients and caregivers understand and recall this information. Observational research could provide insight in how these conversations are conducted and how they could be improved, possibly supported by conversational tools.

We also found that patients and caregivers believe that some diagnostic tests, such as performing lumbar puncture for cerebrospinal fluid biomarker, provide more certainty on the eventual diagnosis than others. This is particularly interesting because it suggests that diagnostic testing can provide absolute certainty. The question rises whether patients and caregivers are aware that interpreting test results can be difficult for clinicians and that biomarkers results can be (borderline) abnormal. Although patients and caregivers search for certainty, uncertainty remains inherently implicated in the outcome of diagnostic testing, especially in the predementia stage.

The importance of the caregiver in dementia patients' care has been acknowledged before [11,15]. Our study showed that caregivers have a strong information need and a prominent role in decision making. We also showed that this prominent role can be burdensome. Where patients and caregivers used to be one team, this relationship is changing and their views and goals start to drift apart. Caregivers still show great loyalty to their significant other and even minimize the patient's symptoms when asked to describe those. As the workload of caring for their significant other increases, their capacity seems to decrease because of the social, emotional, and practical implications of the patient's disease [16]. The involvement of a psychologist or (specialized) nurse was therefore highly valued by these caregivers, especially in light of the experienced time constraints with the clinician.

In the past few decades, SDM has garnered momentum, but still little is known about communication and SDM in dementia care, and specifically in diagnostic testing for AD. Together with our study on clinicians' views [9], the present study is a valuable first step in providing insight in these topics. A few possible limitations should however be

Table 5
Patients' and caregivers' views regarding implications of diagnosis and/or test results

Coping with a diagnostic label

C11.2: of course it is hereditary and I am my father's child, my child is also my child, so do you want to know all about it?

C22: But I found that really upsetting, I found it a quite upsetting label. (...) I find it liberating to talk about it (...) because it's been quite difficult for many years

P33: The word Alzheimer's is like a curse that you hear. (...) [it] is seen as an incurable disease and you have that hanging over you

C22: If you get a diagnosis of Alzheimer's, it comes as a confirmation (...) [patient] immediately felt like a patient (...) So my reaction was, did we really need to know? C23: I also thought that briefly

Need for information on prognosis/future

[Interviewer: how will it be in six months' time, in five years, did they discuss that with you?] P22: no, not really no. P21: it seems as if they dare not do that.

P22: [it] was said, however, that there are certain things that they cannot predict. (...) P23: how will it develop, can you explain a bit more, well that will all be discussed at one of the later occasions I guess.

C11.2: [about the Internet] for example, it says: life expectancy 2 to 10, 15 years. How long has he had it? Has he had it for 10 years, has he only got 5 years left? (...) C13: You do expect a bit more, perhaps that he could tell you that straight away (...) he is the doctor.

C23: That we were a bit disappointed (...) that we were told nothing about what we can do about it.

considered. First, our qualitative focus group method allowed us to assess a broad range of views and experiences but limited us in making statements on how many patients and caregivers share these views. Second, we only included patients and caregivers who actually visited one of the memory clinics, hence excluding those who did not get referred by their general practitioner or who did not even seek help in the first place. Indisputably, however, combined results of both studies highlight the necessity for a more thorough evaluation of how conversations on decision making and test result are conducted and suggest on which hurdles such research should focus. In an observational follow-up study, we are examining communication and decision-making processes during prediagnostic and postdiagnostic clinician-patient encounters, aiming to eventually provide clinicians with the necessary knowledge, skills, and tools to improve these conversations.

In conclusion, our study showed that both the decision-making process on diagnostic testing for AD and the conversations about test results can be improved to meet patients' and caregivers' needs to be more involved and receive

more information; especially on, as one patient summarized "details, emotions, and implications." We showed several discrepancies between what clinicians believe they usually discuss, and what patients and caregivers report was addressed during the prediagnostic and postdiagnostic encounters. Conversations about decision making and test results could possibly be improved by increasing clinicians' awareness of patients' and caregivers' involvement and information needs and providing them with the necessary knowledge, tools, and skills to successfully conduct these conversations.

Acknowledgments

The authors thank all the participating patients and caregivers for their efforts. The authors also thank Sanne Schepers for her contribution in recruiting participants and checking the transcripts. This study is funded by ZonMW-Memorabel (ABIDE; grant number 70.73305-98-205), a project in the context of the Dutch Deltaplan Dementie. The authors thank ZonMw Memorabel for its support. Study

Table 6
Patients' and caregivers' views regarding other relevant experiences of communication and care

Caregivers' prominent role in the clinical encounter

C14: And I'm going to name it all, yes that is not very nice, because I do still love my husband (...) [patient] later said, you were running me down. (...) So I end up giving acceptable answers, I do try to be honest, but I frame it as if things are not so bad.

C15: So the two of you are sitting there and [patient] was first allowed to explain everything and then I was asked: "Would you like to give your view?" And I thought, how can I say that without hurting her feelings? (...) I had to correct a lot of what she had said. (...)

C11.2: Sometimes [they] speak as if he already can't understand anything anymore. That's really difficult, quite upsetting. (...) He said it himself when we got home, he said: yes, that information isn't really for me, because they just look at you and not at me.

C14: I deliberately avoid looking at the doctor, because otherwise they always look at me (...) I deliberately did this [looks upwards], and then the doctor asked: are you looking for something? But I did that on purpose, they need to look at [patient]!

Patient and caregiver cannot always be considered to be a "team" anymore

C11.2: Under the pretext of a prostate check, I made an appointment [with the GP] but actually rang the doctor in advance asking to also look at that. And then she started to broach the subject, because that is rather difficult.

Time limitations

C22: And I did have the feeling that we needed to get away quickly, so we may not have much time to talk about it. (...) After that, we had a conversation with the medical psychologist, which was good, because they have more time. (...) and I do understand that the neurologist is not there to take care of you, it's actually quite a formal conversation.

C13: A very brief explanation, it felt as if you were back in the corridor with your diagnosis within 10 minutes.

P15: [doctor] was just very business-like, you have this and that, and do you have any questions?

sponsors had no involvement in the study design, the collection, analysis or interpretation of the data, the writing of the article, or the decision to submit the article for publication.

RESEARCH IN CONTEXT

1. Systematic review: Little is known about patients' and caregivers' preferences for involvement in decision making around diagnostic testing for Alzheimer's disease (AD).
2. Interpretation: Patients and caregivers prefer to be actively involved in a process of shared decision making in deciding about diagnostic testing for AD. They perceived an active role in decision making, but decisions were mostly made before the first encounter at the memory clinic. It often remains unclear to patients and caregivers why certain diagnostic tests were used. They also have a strong need for more information on the results of these tests, on the extent to which the results were (ab)normal, and on the implications of these test results for the prognosis and daily life.
3. Future directions: Observational research is needed to assess conversations and decision making behaviors in routine care.

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APPENDIX

ABIDE study group

Amsterdam, the Netherlands (Alzheimer Center and Department of Neurology, Amsterdam Neuroscience, VU University Medical Center): Wiesje M. van der Flier, PhD, Philip Scheltens, MD, PhD, Femke H. Bouwman, MD, PhD, Marissa D. Zwan, PhD, Ingrid S. van Maurik, MSc, Arno de Wilde, MD, Wiesje Pelkmans, MSc, Colin Groot, MSc, Ellen Dicks, MSc, Els Dekkers (Department of Radiology and Nuclear Medicine, Amsterdam Neuroscience, VU University Medical Center), Bart N.M. van Berckel, MD, PhD, Frederik Barkhof, MD, PhD, Mike P. Wattjes, MD, PhD (Neurochemistry laboratory, Department of Clinical Chemistry, Amsterdam Neuroscience, VU University Medical Center), Charlotte E. Teunissen, PhD, Eline A. Willemse, MSc (Department of Medical Psychology, University of Amsterdam, Academic Medical Center) Ellen M. Smets, PhD, Marleen Kunneman, PhD, Sanne Schepers, MSc (BV Cyclotron), E. van Lier, MSc; Haarlem, the Netherlands (Spaarne Gasthuis): Niki M. Schoonenboom, MD, PhD; Utrecht, the Netherlands (Department of Neurology and Neurosurgery, Brain Center Rudolf Magnus, University Medical Center Utrecht): Geert Jan Biessels, MD, PhD, Jurre H. Verwer, MSc (Department of Geriatrics,

University Medical Center Utrecht), Dieneke H. Koek, MD, PhD (Department of Radiology and Nuclear Medicine), Monique G. Hobbelen, MD (Vilans Centre of Expertise in Long-Term Care), Mirella M. Minkman, PhD, Cynthia S. Hofman, PhD, Ruth Pel, MSc; Meppel, the Netherlands (Espria): Esther Kuiper, MSc; Berlin, Germany (Piramal Imaging GmbH): Andrew Stephens, MD, PhD; Rotkreuz, Switzerland (Roche Diagnostics International Ltd.): Richard Bartra-Utermann, MD.

Memory clinic panel

The members of the memory clinic panel are as follows: Niki M. Schoonenboom, MD, PhD (Spaarne Gasthuis, Haarlem); Barbera van Harten, MD, PhD, Niek Verwey, MD, PhD, and Peter van Walderveen, MD (Medisch Centrum Leeuwarden, Leeuwarden); Ester Korf, MD, PhD (Admiraal de Ruyter Ziekenhuis, Vlissingen); Gerwin Roks, MD, PhD (Sint Elisabeth Ziekenhuis, Tilburg); Bertjan Kerklaan, MD, PhD (Onze Lieve Vrouwe Gasthuis, Amsterdam); Leo Boelaarts, MD (Medisch Centrum Alkmaar, Alkmaar); Annelies. W.E. Weverling, MD (Diaconessenhuis, Leiden); Rob J. van Marum, MD, PhD (Jeroen Bosch Ziekenhuis, 's-Hertogenbosch); Jules J. Claus, MD, PhD (Tergooi Ziekenhuis, Hilversum); Koos Keizer, MD, PhD (Catherina Ziekenhuis, Eindhoven).