

Diagnostic Assessment & Prognosis

Clinician-patient communication during the diagnostic workup: The ABIDE project

Leonie N. C. Visser^{a,b,*}, Marleen Kunneman^{c,d}, Laxsini Murugesu^a, Ingrid van Maurik^{b,e},
Marissa Zwan^b, Femke H. Bouwman^b, Jacqueline Schuur^f, Hilje A. Wind^g,
Marjolijn S. J. Blaauw^h, J. Jolijn Kragtⁱ, Gerwin Roks^j, Leo Boelaarts^k, Annemieke C. Schipper^l,
Niki Schooneboom^m, Philip Scheltens^b, Wiesje M. van der Flier^{b,e}, Ellen M. A. Smets^a

^aDepartment of Medical Psychology, Amsterdam Public Health research Institute, University of Amsterdam, Amsterdam UMC, Amsterdam, The Netherlands

^bDepartment of Neurology, Alzheimer Center Amsterdam, Amsterdam Neuroscience, Vrije Universiteit Amsterdam, Amsterdam UMC, Amsterdam, The Netherlands

^cKnowledge and Evaluation Research (KER) Unit, Mayo Clinic, Rochester, USA

^dDepartment of Biomedical Data Sciences, Medical Decision Making, Leiden University Medical Center, Leiden, The Netherlands

^eDepartment of Epidemiology and Biostatistics, Vrije Universiteit Amsterdam, Amsterdam UMC, Amsterdam, The Netherlands

^fDepartment of Clinical Geriatrics, Tergooi Hospital, Blaricum, The Netherlands

^gDepartment of Clinical Geriatrics, Spaarne Gasthuis, Haarlem, The Netherlands

^hGeriatric Center, Medical Center Leeuwarden, Leeuwarden, The Netherlands

ⁱDepartment of Neurology, Reinier de Graaf Gasthuis, Delft, The Netherlands

^jDepartment of Neurology, Elisabeth-TweeSteden Ziekenhuis, Tilburg, The Netherlands

^kGeriatric Department, NoordWest Ziekenhuis Groep, Alkmaar, The Netherlands

^lDepartment of Neurology, LangeLand Ziekenhuis, Zoetermeer, The Netherlands

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

Abstract

Introduction: We aimed to describe clinician-patient communication in the diagnostic process of memory clinics, specifically clinician behavior known to facilitate knowledgeable participation of patients during consultations.

Methods: In this multicenter, observational study, we audio-recorded routine diagnostic consultations of 41 clinicians and 136 patients/caregivers at eight memory clinics. Patients/caregivers completed surveys after each audiotaped consultation. We used a study-specific coding scheme to categorize communication behavior.

Results: Clinicians often provided information on (results of) diagnostic testing. They infrequently invited questions and/or checked understanding. Clinician behavior to involve patients in decision-making about diagnostic testing was limited. Of note, patients/caregivers rarely expressed their information or involvement preferences. Yet, approximately, one quarter of them would have liked to receive more information.

Discussion: Involving patients more explicitly by means of shared decision-making could benefit the quality of care provided in memory clinics because it enables clinicians to attune the diagnostic workup to the individual patient's needs.

Leonie N.C. Visser, Marleen Kunneman, Laxsini Murugesu, Ingrid van Maurik, Marissa Zwan, Femke H. Bouwman, Jacqueline Schuur, Hilje A. Wind, Marjolijn S.J. Blaauw, J. Jolijn Kragt, Gerwin Roks, Leo Boelaarts, Annemieke C. Schipper, Niki Schooneboom, and Ellen M.A. Smets declare no conflict of interests. Prof. Dr. Philip Scheltens has acquired grant support (for the institution) from GE Healthcare, Danone Research, Piramal, and MERCK. In the past 2 years, he has received consultancy/speaker fees (paid to the institution) from Lilly, GE Healthcare, Novartis, Sanofi, Nutricia, Probiobrug, Biogen, Roche, Avraham, and EIP Pharma. Prof. Dr. Wiesje M. van der Flier performs contracted research for Biogen MA Inc.

Her research programs have been funded by ZonMW, Health Holland, Pasmans stichting, NWO, EU-FP7, EU-JPND, Alzheimer Nederland, Cardiovasculair Onderzoek Nederland, stichting Dioraphte, Gieskes-Strijbis fonds, Boehringer Ingelheim, Piramal Neuroimaging, Roche BV, Janssen Stellar, and Combinostics. All funding is paid to the institution.

*Corresponding author. Tel.: +31(0)204440823; Fax: +31(0) 204448529.

E-mail address: n.c.visser@amsterdamumc.nl

© 2018 The Authors. Published by Elsevier Inc. on behalf of the Alzheimer's Association. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords:

Doctor-patient communication; Alzheimer's disease; Dementia; Diagnostic work-up; Patient engagement; Shared decision-making

1. Introduction

To realize full benefit of early diagnostic care in memory clinics, it is important that patients are engaged in decisions regarding their health and care, that is, that they participate knowledgeably and actively [1,2]. This is particularly relevant to decisions pertaining to diagnostic testing [3] because diagnostic testing for Alzheimer's disease (AD) can have advantages and disadvantages. Early detection of disease and at-risk individuals is crucial for future targeted prevention of dementia [4,5]. Yet, early diagnosis may have drawbacks for the individual, such as social stigmatization or psychological distress [6–8], especially because no adequate treatment is (yet) available. Still, a timely diagnosis could benefit patients and their caregivers, by enabling them to be more actively engaged in their health/disease management and prepare for the future [7,9]. Thereby, contributing to improved patient experiences of quality of care and life [6,10].

Given that individual patients weigh potential benefits and harms differently, decisions for or against diagnostic testing are considered “preference sensitive” [3]. Therefore, clinicians and patients should engage in a process of shared decision-making to ensure that diagnostic decisions are made that best fit the individual [11]. However, patients are confronted with an increasing amount of complex information and choices, despite of their (potential) cognitive decline. Memory clinic clinicians could thus play a key role in supporting patients and caregivers to be well-informed and actively involved during diagnostic consultations. Survey and focus group studies, however, suggest that patients' communication and engagement needs are often not met, and clinicians miss crucial opportunities to facilitate patient engagement in the diagnostic process [3,12–15]. Yet, empirical data on actual clinician-patient communication and decision-making during diagnostic care at memory clinics are scarce [16].

Therefore, the aim of this observational study was to describe naturalistic clinician-patient communication during routine diagnostic clinical consultations in a wide range of memory clinics. We specifically focused on clinician behavior known to facilitate knowledgeable participation of patients during these consultations: (1) upfront agenda setting (what is this consultation about and how can patients contribute?), (2) informing on diagnostic tests, test results, diagnosis, and implications thereof, (3) promoting understanding, for example, by inviting questions, and (4) involving patients in decision-making regarding diagnostic testing. Furthermore, we observed whether patients and caregivers initiated a conversation on diagnostic testing

and expressed their preferences regarding information provision and involvement in decision-making. In addition, we surveyed their evaluation of the provided information and decision-making process.

2. Methods

2.1. Design

This observational study was conducted as part of the ABIDE project [17]. ABIDE has been designed to improve the diagnosis of AD in clinical practice, taking into account patients' preferences toward diagnostic testing and communication of test results. For the present study, we audio-recorded consultations between clinicians, patients, and their caregivers during the routine diagnostic workup for dementia. Clinicians completed a survey at the start of the study, and patients/caregivers completed surveys after each audiotaped clinical consultation. Information on diagnostic tests used and diagnosis was retrieved from patients' medical records.

All participants provided written informed consent (for their consultations to be audiotaped). The board of the Medical Ethics Committee of the Academic Medical Center in Amsterdam reviewed this study.

2.2. Participants

We included 136 patients seen as a part of routine clinical care by 41 clinicians at eight Dutch memory clinics, located at one academic hospital (20 patients, 12 clinicians), six nonacademic teaching hospitals (106 patients; 27 clinicians), and one nonacademic, nonteaching hospital (10 patients; 2 clinicians). All clinicians working at these memory clinics were eligible and invited, and 41 consented to participate (by self-selection). Their newly referred patients (i.e., in the Netherlands, patients are referred to the memory clinic by their general practitioner or another medical doctor, i.e., no self-referral) and accompanying caregivers were invited to participate. Patients or caregivers with poor comprehension of the Dutch language or who were not able to provide informed consent were not eligible. Patients with Mini-Mental State Examination (MMSE) scores of 17 or lower were not included in the survey part of the study.

2.3. Audio recordings of clinician-patient consultations

Fig. 1 displays a flow chart of study procedures. Audio recordings were made during pretesting consultation(s), that is, the patient's first clinical encounter(s) at the memory

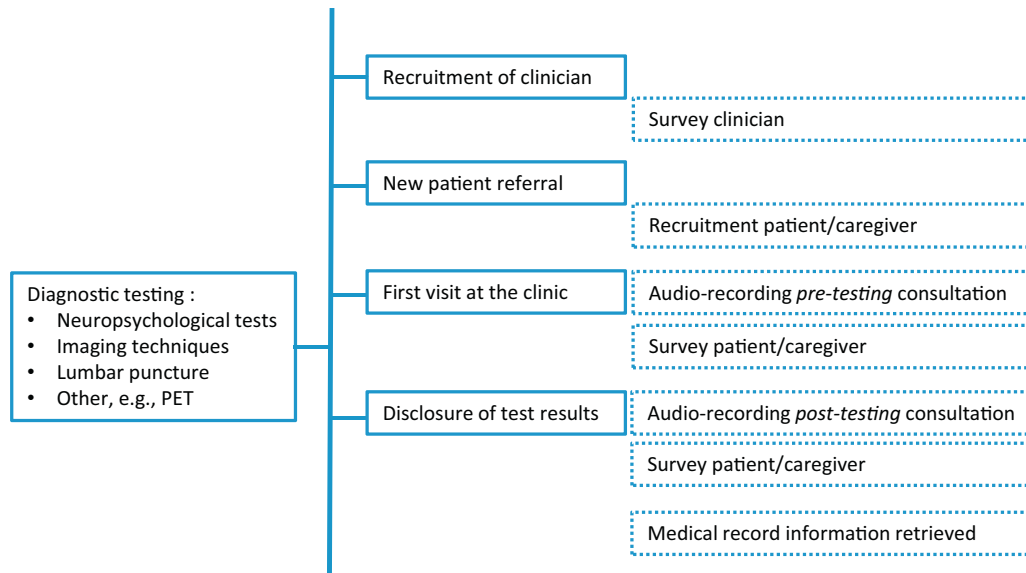


Fig. 1. Flowchart of study procedures. *Notes.* Pretesting consultations took place mostly before (potential) diagnostic testing. Because of variation in diagnostic pathways between memory clinics [18], testing was occasionally scheduled before, yet on the same day as, the first consultation with the clinician. To be still considered pretesting, no test results had to be disclosed. For 43% of patients, more than one pretesting consultation was audiotaped, for example, because patients met with a resident first and later with the supervising clinician. During analyses, we considered these multiple pretesting consultations per patient to be one.

clinic, and post-testing consultation(s), that is, the consultation(s) after diagnostic testing in which test results and, if possible, the diagnosis were discussed. Audio recordings were excluded if (i) only a part of the consultation was audio-recorded, (ii) the patient was not present (i.e., only clinician and caregiver), or (iii) a conversation took place during diagnostic testing procedures. Furthermore, some consultations were not audio-recorded, for example, because of equipment failure or because no post-testing consultation took place.

2.4. Coding clinician-patient communication

A study-specific coding scheme was developed ([Supplementary Material](#)), aimed at categorizing clinicians' communication behavior related to (1) agenda setting, (2) providing information on diagnostic tests, test results, diagnosis, and implications thereof, (3) promoting understanding, and (4) (shared) decision-making regarding diagnostic testing, that is, decisions for or against diagnostic testing in general, whether or not to initiate neuropsychological assessment/testing, structural imaging by means of MRI/CT, amyloid testing by means of lumbar puncture or positron emission tomography, or other relevant diagnostic tests. In addition, we categorized whether the patient/caregiver initiated a conversation on diagnostic testing and expressed their preferences regarding the provision of information and involvement in decision-making. The coding scheme was based on previous work and initial audio recordings [12,19]. The validated Observing PaTient InvOlvement (OPTION12) scale [20] was included to quantify the extent

to which clinicians involved patients in the decision-making process regarding testing. If more than one decision was made, the most optimal behavior observed was coded. Scores are reported on a 0 to 100 scale (0 = no clinician behavior to involve the patient, 100 = most optimal behavior; considering a score of 50 as baseline skill level [21]).

Two trained raters (BA and AH) independently first coded consultations of 19 patients (14%). Inter-rater reliability was calculated using Cohen's kappa, balancing to adjust for uneven distributed matrix when relevant [22]. The resulting adjusted kappa's indicated substantial to almost perfect agreement between raters (mean adjusted $\kappa = 0.89$, range 0.63–1.00) [23]. For the OPTION12 scale, the intraclass correlation coefficient was good (intraclass correlation coefficient = 0.90 [CI, 0.66–0.97]). The remaining audiotapes were then coded by one of the two raters.

2.5. Surveys

Clinicians' characteristics were assessed before audio recordings were made. Patients and caregivers completed a survey immediately or shortly after the pretesting and post-testing consultations. The pretesting survey addressed:

- Patients' information need about the disease and treatment (single item; 11-point Likert scale 0: I want to know as little as possible to 10: I want to know as much as possible).
- Patients' preferred role in decision-making about health care, assessed by an adapted version of the Control Preferences Scale (categories ranged from (1) I

prefer to make the decision alone, through (3) I prefer to make the decision together with the doctor, to (5) I prefer that the doctor makes the decision alone) [24,25].

- Patients'/caregivers' perception of the clinicians' shared decision-making behavior, using the nine-item Shared Decision Making Questionnaire (SDM-Q-9; six-point Likert scale ranging from 0: completely disagree to 5: completely agree) [26]. The sum scores were converted to a 0 to 100 scale, with 100 indicating most optimal behavior.

The post-testing survey comprised

- A selection of items of the European Organization for Research and Treatment of Cancer Quality of Life Group information questionnaire (EORTC QLQ-INFO 25) [27], assessing patients'/caregivers' perceptions and evaluation of the information they received (10 items; four-point Likert scale), and their wishes for more/less information (2 items; no/yes, and one open-ended question).
- A single item asking if they had received written information about the diagnosis (no/yes).

2.6. Medical record

We retrieved information from patients' medical records on their age, gender, MMSE, diagnosis, and diagnostic tests used. Two authors (IvM and LV) independently categorized all patients into one of four broadly defined (syndrome) diagnostic groups: (1) dementia, all patients with (early) dementia; (2) mild cognitive impairment (MCI), all patients labeled with MCI, prodromal AD or with objective cognitive disorder(s) without meeting the criteria for dementia, (3) cognitively normal, all patients without objective cognitive disorders; (4) other/unclear, patients that could not (yet) be categorized into one of the aforementioned. Categorizations were discussed until consensus was reached. If in doubt, a third author (WvdF) was consulted.

2.7. Statistics

IBM SPSS statistics software and descriptive statistics were used to analyze and report characteristics of the sample, coded communication behavior, and survey responses.

3. Results

3.1. Sample descriptives

Tables 1–3 display characteristics of the 136 patients and 41 clinicians, and their consultations. Table 1 includes information on patients' syndrome diagnosis. The pretesting consultations of 125/136 patients (92%) and the post-testing

consultations of 81/136 patients (60%) were available for analysis.

3.2. Clinician-patient communication

3.2.1. Agenda setting

A reason for this encounter was voiced by clinicians in 23/125 (18%) of the pretesting consultations. Most often the voiced reason was to have a conversation on patients' symptoms (21/23), for example, "We are here today because I would like to ask you some questions about your symptoms". There were no reasons voiced relating to diagnostic testing. During the post-testing consultation, the clinician communicated the reason for the encounter more often, in 43/81 (53%) consultations. Almost always this reason was "discussing test results" (41/43).

3.2.2. Providing information

In 74/125 (59%) pretesting consultations, the clinician provided information about diagnostic tests. This could be only one sentence, for example, "I think it is a good idea to make a brain scan" or a longer monolog. Clinicians informed about diagnostic testing in general (30/125; 24%), and/or addressed specific tests: neuropsychological testing (51/125; 41%), imaging by means of MRI/CT (62/125; 50%), lumbar puncture (17/125; 14%), positron emission tomography (4/125; 3%), and/or other tests, mostly laboratory/blood tests (27/125; 22%). In the remaining 51/125 (41%) pretesting consultations, diagnostic tests were only briefly mentioned in relation to the patient's testing schedule, for example, "I will see you again this afternoon, after the MRI" (28/125; 22%), or not mentioned at all (23/125; 18%).

In the post-testing consultations, patients were often provided with the individual test results. Specifically, 79% of patients who underwent neuropsychological testing, 95% of patients who had been tested by means of MRI or CT, 78% of patients who underwent a lumbar puncture, and 11% of patients who were subject to a PET scan (any type of PET scan; for research or clinical purposes) received information on the (ab)normality of their results on that specific test.

Concordance between the diagnosis extracted from the patient's medical record and the communicated diagnosis/diagnostic label was 74% (14/19) for cognitively normal individuals, 80% (28/35) in dementia, and 54% (7/13) in MCI. When not concordant, for cognitively normal and dementia, the clinician mostly communicated that no definitive diagnosis could (yet) be given based on the current test results (e.g., "Actually, we can't give you a diagnosis at this point, because we have too little information to determine what's going on"). Within the MCI group, the clinicians often provided patients with a descriptive conclusion, instead of using the MCI label, for example, "So in summary, some

Table 1
Patient characteristics

Patients	N = 136
Gender (female), %	67/136 (49)
Age in years	M = 70, SD = 10, range = 43–91
Highest level of education, %*	
1-4: primary school/lower level vocational education	39/115 (34)
5-6: general secondary education	43/115 (37)
7: higher level vocational/university education	27/115 (24)
Other	6/115 (5)
Information preference	M = 8.2, SD = 2.1, range = 0–10
Decisional involvement preference, %	
I prefer to make decisions alone	4/113 (4)
I prefer to make decisions, considering the clinician's opinion	33/113 (29)
I prefer to make decisions together with the clinician	55/113 (49)
I prefer that the clinician makes decisions, considering my opinion	16/113 (14)
I prefer that the clinician makes decisions alone	5/113 (4)
Mini-Mental State Examination (MMSE)	M = 25, SD = 5, range = 3–30
Syndrome diagnosis, %†	
Dementia	53/136 (39)
MCI	21/136 (15)
Cognitively normal	34/136 (25)
Other/unclear, including 5 missing	28/136 (21)
Patients that underwent diagnostic testing, %‡	
Neuropsychological testing	68/110 (62)
Imaging techniques (MRI and/or CT)	111/132 (84)
MRI	78/132 (59)
CT	34/132 (26)
Lumbar puncture (CSF)	28/132 (21)
Positron-emission tomography (PET)	9/132 (8)
Amyloid PET	3/132 (2)
FDG PET	1/132 (1)
PET not further specified	6/132 (5)
None of the above§	14/132 (11)

*Classification based on Verhage (1964); data available from 115 patients.

†Syndrome diagnosis/diagnostic label at time of the post-diagnostic testing consultation, based on medical record.

‡Data available from 132 patients; medical record data regarding neuropsychological testing available from 110 patients.

§Only neuropsychological screening by means of MMSE, MOCA, CAMCOG.

abnormalities on the MRI, possibly caused by small vessels in the brain, no dementia”.

In almost all (80/81; 99%) of the post-testing consultations, one or more next steps in care or disease management were discussed (Table 4). These included most often follow-up at the memory clinic (56/81; 69%). Further diagnostic testing was discussed in approximately one-third of consultations (28/81; 35%).

Of note, patients/caregivers almost never initiated the conversation on diagnostic testing (in 3/125 pretesting consultations; 2%). In addition, patients/caregivers rarely ex-

Table 2
Clinician characteristics

Clinicians	N = 41
Gender (female), %	29/41 (71)
Age in years	M = 43, SD = 11, range = 25–66
Medical specialty, %	
Neurologist	17/41 (42)
Geriatrician	13/41 (32)
Other, e.g., resident or specialist nurse	11/41 (27)
Work experience at a memory clinic in years	M = 8, SD = 7, range = 0–25
Number of new patients per month	M = 14, SD = 8, range = 2–30

pressed what kind or how much information they preferred (3/125 of pretesting and 0/81 of post-testing consultations).

3.2.3. Promoting understanding

In 2/125 (2%) pretesting consultations, the clinician showed MRI images that were previously made elsewhere. No other (visual) aids were used to support these conversations. By contrast, in 50/81 (62%) post-testing consultations clinicians used aids to explain test results, most often CT/MRI images (48/81; 59%). In 29/125 (23%) pretesting and in 39/81 (48%) post-testing consultations, the clinician invited patients/caregivers to ask questions. Most often, this happened once (26/29 and 32/39), at the end of the consultation (27/29 and 36/39), by means of a closed question, for example, “Do you have any questions?”. Only in few pretesting (8/125; 6%) and post-testing (15/81; 19%) consultations, the clinician explicitly checked understanding of provided information. Most often by means of a closed question, for example, “Is everything clear?”, and never by asking the patient/caregiver to repeat or summarize what had been discussed.

3.2.4. (Shared) decision-making

In almost all pretesting consultations in which diagnostic testing was addressed (70/74), one or more decisions were made on testing. Clinicians often presented decisions implicitly, that is, as a recommendation or strong advice rather than an option for which patients' preferences mattered. In 57/74 (77%) of these consultations, at least one of such recommendations was voiced (e.g., “I would propose to do an MRI”); in two consultations, the recommendation

Table 3
Characteristics of the recorded pretesting and post-testing consultations

Consultations	Pretesting (N = 125)	Post-testing (N = 81)
Patients accompanied by a caregiver, %	112/125 (90)	76/81 (94)
spouse/partner	78/125 (62)	51/81 (63)
daughter/son (in law)	25/125 (20)	17/81 (21)
other	9/125 (7)	8/81 (10)
Total duration in minutes	M = 49, SD = 23, range = 11–112	M = 19, SD = 13, range = 3–97

Table 4

Next steps in care or disease management addressed in the post-testing consultation

Next steps/implications discussed	Ratio (%)
Follow-up at the memory clinic	56/81 (69)
Initiating/referring to other medical and paramedical care	45/81 (56)
Medication	40/81 (49)
Contact with general practitioner	39/81 (48)
Lifestyle adjustment, e.g., advice in relation to diet or exercise	36/81 (44)
Further diagnostic testing	28/81 (35)
Driving ability testing	19/81 (24)
Study participation: research/trials	15/81 (19)
Genetic testing	3/81 (4)
Second opinion	0/81 (0)
Other	4/81 (5)
None	1/81 (1)

was requested by the patient/caregiver (e.g., “What would you advise?”).

Observed clinician behavior to involve the patient in the decision-making process was limited, with a mean OPTION12 score of 16.6 ± 12.8 (min-max: 0–54) when considering initiating diagnostic testing, and 19.2 ± 11.9 (min-max: 2–42) when relating to further diagnostic testing in the post-testing consultations. Of note, these mean scores only reflect consultations in which diagnostic testing was addressed. In addition, patients/caregivers rarely expressed if and how they would like to be involved in decision-making (in 3/125 pretesting consultations; 2%).

3.3. Patients' and caregivers' perceptions and satisfaction

The completed surveys showed that patients and caregivers perceived clinicians' behavior to involve patients in diagnostic decision-making to be 58 ± 26 ($M \pm SD$; patients) and 59 ± 27 ($M \pm SD$; caregivers) on a scale from 0 to 100.

On a four-point Likert scale ranging from 1 to 4, patients and caregivers perceived to have received a moderate amount of information about diagnostic testing and their disease (Table 5). They viewed this information as quite helpful and were quite satisfied with this information. Roughly one quarter of patients (20/78; 26%) and caregivers (15/76; 20%) reported to have received written information. A similar proportion (16/78; 21% of patients and 18/76; 24% of caregivers) indicated that they would have liked to receive more information, especially about the expected course of the disease/symptoms. Of note, only one patient and none of the caregivers would have liked to receive less information.

4. Discussion

In this multicenter study, we gathered empirical data on clinician-patient communication in memory clinics during the diagnostic workup for dementia. Our main finding is that clinicians often provided information about diagnostic tests beforehand and (implications of) test results afterward, but they showed limited behavior to facilitate engagement of

Table 5

Patients' and caregivers' perceptions of information received

Perceptions	Patients		Caregivers	
	M	SD	M	SD
Perception of the amount of information received on:				
The goal of diagnostic testing/tests	2.7	0.8	2.7	0.9
How diagnostic testing went	2.6	0.9	2.8	0.8
Test results	2.8	0.9	2.6	1.7
Side/negative effects of diagnostic tests	1.9	1.0	3.2	0.8
The diagnosis	2.4	0.9	2.2	1.5
The impact of the disease on daily life	2.0	1.0	2.2	1.0
How to deal/cope with the disease	1.9	0.9	2.2	1.0
The expected symptoms	1.8	0.9	2.0	0.9
Satisfaction with the information received	3.0	0.8	3.1	0.8
Usefulness of the information received	3.0	0.8	3.3	0.8

NOTE. All items were answered on a four-point Likert scale ranging from 1: no information to 4: a lot of information, or 1: not at all satisfied/useful to 4: very much satisfied/useful. Survey data were available from 69 to 100% of patients and 66 to 100% of caregivers, depending on the scale/item. The lower percentages were due to missing surveys and missing responses on specific scales because some items were considered as not applicable by patients/caregivers.

patients/caregivers in their consultations and in decision-making about diagnostic testing. This is unfortunate because most patients reported a preference to be involved. However, patients/caregivers seldom showed initiative in these consultations to express their preferences for decisional involvement or information, or to start a conversation on diagnostic testing.

Our results extend on the scarce available literature regarding clinician-patient communication during the diagnostic process, by adding empirical data [12–15,19]. Earlier studies mostly used interviews and focus groups, and found that memory clinic patients and their caregivers perceive communication with clinicians not necessarily as a dialog [14]. Indeed, one previous observational study indicated that clinicians take up over 80% of the speaking time during disclosure consultations in the context of dementia, leaving only 20% for patients/caregivers [15]. The present observational study took the next step in research on clinician-patient communication in this context, by categorizing a range of communication practices based on audio recordings of actual consultations, supplemented with survey and medical record data.

With regard to agenda setting, clinicians often started the consultation by asking questions or providing information as is common in diagnostic consultations. However, they did not explain upfront that a decision about diagnostic testing was at stake. Consequently, patients may not have known whether/how to contribute. Creating choice awareness is

the first step of shared decision-making [3], and this could be achieved by explicitly stating, as a reason for the consultation, that a decision on diagnostic testing needs to be made depending on patient's preferences [28]. From other medical fields, we know that fostering choice awareness promotes other shared decision-making steps, such as discussing what is important to patients [28]. Thus, by not setting an agenda upfront, clinicians miss opportunities to facilitate shared decision-making.

Informing patients on diagnostic testing was not a standard part of prediagnostic testing consultations, whereas the great majority of patients subsequently underwent testing. In addition, individual test results were often, but not always disclosed by clinicians. This could explain why, in previous research, patients and caregivers reported to have 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 [12,13]. Because further diagnostic testing was discussed as a next step in one-third of the postdiagnostic testing consultations, it is possible that clinicians did not (yet) want to share specific test results because these were inconclusive and clinicians might fear that these would only result in (more) uncertainty or confusion. However, information about previous (inconclusive) test results and the subsequent reasons for further testing is essential to enable involvement of patients/caregivers in this decision. We also observed variation in whether the clinician addressed other next steps and/or implications of test results, such as lifestyle adjustment or medication. This might explain why a considerable proportion of patients and caregivers reported unmet information needs, especially about the future. Alternatively, patients and caregivers might have forgotten pieces of provided information, possibly because of the complex and emotional nature of many of these diagnostic conversations [29].

Remarkably, most clinicians demonstrated little behavior to stimulate patients'/caregivers' understanding and recall of provided information. Our sample consisted of equal parts of individuals with mild or without cognitive impairment and individuals with dementia. Many patients were thus capable to process information about diagnostic testing, at least to some extent. They could, however, use some encouragement. Moreover, in case of dementia, the accompanying caregiver needs to understand what is going on. Using communication strategies known to promote understanding, and subsequent disease management, therefore seems relevant. As such, the teach-back method [30] is a promising technique in which the clinician asks the patient to repeat back key points of the provided information (e.g., "Can you tell me in your own words what we have discussed so far?"). Our observational study showed that this technique was never applied. In addition, the great majority of patients and caregivers reported not to have received written information about, or a written summary of, the patient's diagnosis. To stimulate their understanding and recall of information essential for them to cope with their situation, we recommend the use of a written summary of the pa-

tient's diagnosis and implications thereof in clinical practice, in agreement with the guidelines by Grill et al. [31].

Decision-making regarding both initial and further diagnostic testing was observed relatively infrequently, possibly because of a fixed diagnostic care path within some memory clinics, that is, they used a standard diagnostic protocol in which the decisions regarding diagnostic testing were already made on a memory clinic level (what tests to use and in which order) [12,19]. If a decision was made during the consultation, this decision was often implicit, and clinicians' behavior to involve patients/caregivers in the decision-making process was limited, albeit comparable with observations in other medical contexts [21]. In a former study, clinicians indicated that they, ultimately, believe that diagnostic testing decisions should be made by the clinician, although they value patients' involvement [19]. This may explain our findings. This is unfortunate though because the process of shared decision-making would allow clinicians to attune the diagnostic work-up to what is most relevant to the individual patient [11]. In shared decision-making, four steps are distinguished: (1) the clinician informs the patient that a preference-sensitive decision is to be made (i.e., creating choice awareness); (2) the clinician explains the options including pros and cons; (3) the clinician and the patient discuss what is important for the patient in his/her situation; (4) the clinician and patient discuss the patient's preferred role in decision-making, and make a decision [32]. In general, this approach may reduce practice variation, encourage health-promoting behaviors, reduce inappropriate or unnecessary use of care, and improve patient and clinician satisfaction [11,33].

Patients/caregivers, in turn, did not start a conversation on testing, nor did they express their preferences for information or decisional involvement. Indirectly, this may be related to clinicians' behavior, that is, patients/caregivers may not have felt invited to participate in decision-making. Alternatively, they may have been hindered, by their cognitive impairment, older age, lower educational level, or a lack of relevant knowledge [34]. Their lack of initiative might have caused clinicians to underestimate patients'/caregivers' desired level of involvement in decision-making. Asking patients/caregivers for their preferred level of involvement may be a good way to solve this issue.

Among the strengths of our study is that we gathered empirical data during actual clinician consultations in a variety of memory clinics, including a heterogeneous group of patients and clinicians. Among the potential limitations is a participation bias among clinicians, which might have resulted in a sample of clinicians who are relatively comfortable with communication research and perhaps more skilled. Furthermore, generalizability of our results is potentially limited as we performed this multicenter study in the Netherlands. International replication is therefore warranted and may provide additional, culturally flavored information. In addition, research should investigate (i) potential barriers and facilitators to shared decision-making [34], (ii) factors

that could explain or predict clinician communication, for example, clinician characteristics such as medical specialty or patient characteristics such as diagnosis or age, and (ii) the impact of specific communication strategies by clinicians on patient/caregiver outcomes.

The insights gained from the present study could inform the development of clinician- and patient/caregiver-targeted interventions that facilitate active involvement of patients/caregivers during diagnostic consultations and in decision-making about diagnostic testing. We previously developed ADappt, a prototype web application for clinicians working in memory clinics aimed at supporting information provision and shared decision-making in the diagnostic workup for dementia, and facilitating the calculation and communication of individually tailored risk estimates in patients with MCI [35]. In addition, for clinicians, the development of a communication skills training is warranted, that teaches them strategies and skills crucial to engage patients/caregivers in the decision-making process [32]. For patients and caregivers, enhancing prior knowledge about available options for testing and their (potential) benefits and harms, and stimulating active involvement in consultations may be appropriate. This may be achieved by a question prompt list or (elements of) a decision aid, such as a value clarification exercise [36], aimed at supporting patients/caregivers to make a decision about diagnostic testing that is consistent with their values [37,38].

5. Conclusion

This observational clinical-encounter study shows that, overall, clinicians inform their patients about (results of) diagnostic testing. Yet, they show limited behavior to promote understanding of the provided information and to engage patients/caregivers in decisions regarding diagnostic testing. Involving patients more explicitly by means of shared decision-making could benefit the quality of care provided in memory clinics because it allows clinicians to attune the diagnostic workup to the individual patient. Shared decision-making would thus enable a personalized approach to diagnostic care, allowing patients and caregivers to be more actively involved in (future) treatment decisions, health care and disease management.

Acknowledgments

The authors thank Bahar Azizi, Anneke Hellinga, and Sonja van Gils for their assistance during data collection and/or coding. Research of the Alzheimer center Amsterdam is part of the neurodegeneration research program of Amsterdam Neuroscience. The Alzheimer Center Amsterdam is supported by Stichting Alzheimer Nederland and Stichting VUmc fonds. This study is funded by ZonMW-Memorabel (ABIDE; project No 733050201), a project in the context of the Dutch Deltaplan Dementie. This study was made possible through a grant from the Den Hartog family after

the passing away of Mr Den Hartog, who suffered from Alzheimer's disease. The chair of prof. Wiesje van der Flier is supported by the Pasman stichting. These funding sources were not involved in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.dadm.2019.06.001>.

RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed existing literature to find studies relevant to clinician-patient communication and patient engagement in the memory clinic setting. Most studies collected self-reported data using a focus-group or survey approach. These publications are appropriately cited. Yet, empirical data on actual clinician-patient communication during diagnostic care at memory clinics are scarce.
2. Interpretation: Our findings are consistent with the previously published work, and confirm that a two-way flow of information about diagnostic testing is seldom achieved. Clinicians often inform their patients. Yet, they show limited behavior to promote understanding and involve patients/caregivers in the decision-making process. Of note, patients/caregivers seldom express their preferences in the interaction with their clinician.
3. Future directions: Future research should explore ways to improve knowledgeable participation of patients/caregivers during the diagnostic workup for dementia, for example, by developing clinician- and patient/caregiver-targeted interventions that facilitate involvement of patient/caregivers during consultations and shared decision-making about diagnostic testing.

References

- [1] Gruman J, Rovner MH, French ME, Jeffress D, Sofaer S, Shaller D, et al. From patient education to patient engagement: implications for the field of patient education. *Patient Educ Couns* 2010;78:350–6.
- [2] Menichetti J, Graffigna G, Steinsbekk A. What are the contents of patient engagement interventions for older adults? A systematic review of randomized controlled trials. *Patient Educ Couns* 2018; 101:995–1005.

- [3] van der Flier WM, Kunneman M, Bouwman FH, Petersen RC, Smets EMA. Diagnostic dilemmas in Alzheimer's disease: room for shared decision making. *Alzheimers Dement* (N Y) 2017;3:301-4.
- [4] Wang J, Tan L, Yu JT. Prevention trials in Alzheimer's disease: current status and future perspectives. *J Alzheimers Dis* 2016;50:927-45.
- [5] Carrillo MC, Brashear HR, Logovinsky V, Ryan JM, Feldman HH, Siemers ER, et al. Can we prevent Alzheimer's disease? Secondary "prevention" trials in Alzheimer's disease. *Alzheimers Dement* 2013;9:123-131.e1.
- [6] Dubois B, Padovani A, Scheltens P, Rossi A, Dell'Agnello G. Timely diagnosis for Alzheimer's disease: a literature review on benefits and challenges. *J Alzheimers Dis* 2016;49:617-31.
- [7] de Wilde A, van Buchem MM, Otten RHJ, Bouwman F, Stephens A, Barkhof F, et al. Disclosure of amyloid positron emission tomography results to individuals without dementia: a systematic review. *Alzheimers Res Ther* 2018;10:72.
- [8] Lingler JH, Roberts JS, Kim H, Morris JL, Hu L, Mattos M, et al. Amyloid positron emission tomography candidates may focus more on benefits than risks of results disclosure. *Alzheimers Dement* (Amst) 2018;10:413-20.
- [9] Werner P, Karnieli-Miller O, Eidelman S. Current knowledge and future directions about the disclosure of dementia: a systematic review of the first decade of the 21st century. *Alzheimer's Dement* 2013;9:e74-88.
- [10] Higgins T, Larson E, Schnall R. Unraveling the meaning of patient engagement: a concept analysis. *Patient Educ Couns* 2017;100:30-6.
- [11] Stiggelbout AM, van der Weijden T, De Wit MP, Frosch D, Legare F, Montori VM, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;344:e256.
- [12] Kunneman M, Pel-Littel R, Bouwman FH, Gillissen F, Schoonenboom NSM, Claus JJ, et al. Patients' and caregivers' views on conversations and shared decision making in diagnostic testing for Alzheimer's disease: the ABIDE project. *Alzheimers Dement* (N Y) 2017;3:314-22.
- [13] Abley C, Manthorpe J, Bond J, Keady J, Samsi K, Campbell S, et al. Patients' and carers' views on communication and information provision when undergoing assessments in memory services. *J Health Serv Res Policy* 2013;18:167-73.
- [14] Manthorpe J, Samsi K, Campbell S, Abley C, Keady J, Bond J, et al. From forgetfulness to dementia: clinical and commissioning implications of diagnostic experiences. *Br J Gen Pract* 2013;63:e69-75.
- [15] Sakai EY, Carpenter BD. Linguistic features of power dynamics in triadic dementia diagnostic conversations. *Patient Educ Couns* 2011;85:295-8.
- [16] Dooley J, Bailey C, McCabe R. Communication in healthcare interactions in dementia: a systematic review of observational studies. *Int Psychogeriatrics* 2015;27:1277-300.
- [17] de Wilde A, van Maurik IS, Kunneman M, Bouwman F, Zwan M, Willemse EA, et al. Alzheimer's biomarkers in daily practice (ABIDE) project: rationale and design. *Alzheimers Dement* (Amst) 2017;6:143-51.
- [18] Kunneman M, Bouwman FH, Smets EMA, van der Flier WM. Diagnostiek van dementie: praktijkvariatie in Nederlandse geheugenpoliklinieken. *Neuropraxis* 2018;22.
- [19] Kunneman M, Smets EMA, Bouwman FH, Schoonenboom NSM, Zwan MD, Pel-Littel R, et al. Clinicians' views on conversations and shared decision making in diagnostic testing for Alzheimer's disease: the ABIDE project. *Alzheimers Dement* (N Y) 2017;3:305-13.
- [20] Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing M, Cheung WY, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expect* 2005;8:34-42.
- [21] Couet N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expect* 2013;18:542-61.
- [22] Sim J, Wright CC. The kappa statistic in reliability studies: use, interpretation, and sample size requirements. *Phys Ther* 2005;85:257-68.
- [23] Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977;33:159-74.
- [24] Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res* 1997;29:21-43.
- [25] Salkeld G, Solomon M, Short L, Butow PN. A matter of trust—patient's views on decision-making in colorectal cancer. *Health Expect* 2004;7:104-14.
- [26] Kriston L, Scholl I, Holzel L, Simon D, Loh A, Harter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns* 2010;80:94-9.
- [27] Arraras JI, Greimel E, Chie WC, Sezer O, Bergenmar M, Costantini A, et al. Information disclosure to cancer patients: EORTC QLQ-INFO25 questionnaire. *Expert Rev Pharmacoecon Outcomes Res* 2011;11:281-6.
- [28] Kunneman M, Branda ME, Hargraves I, Pieterse AH, Montori VM. Fostering choice awareness for shared decision making: a secondary analysis of video-recorded clinical encounters. *Mayo Clin Proc Innov Qual Outcomes* 2018;2:60-8.
- [29] Visser LNC, Tollenaar MS, de Haes H, Smets EMA. The value of physicians' affect-oriented communication for patients' recall of information. *Patient Educ Couns* 2017;100:2116-20.
- [30] Ha Dinh TT, Bonner A, Clark R, Ramsbotham J, Hines S. The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: a systematic review. *JBIM Database Syst Rev Implement Rep* 2016;14:210-47.
- [31] Grill JD, Apostolova LG, Bullain S, Burns JM, Cox CG, Dick M, et al. Communicating mild cognitive impairment diagnoses with and without amyloid imaging. *Alzheimers Res Ther* 2017;9:35.
- [32] Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns* 2015;98:1172-9.
- [33] Berger ZD, Brito JP, Ospina NS, Kannan S, Hinson JS, Hess EP, et al. Patient centred diagnosis: sharing diagnostic decisions with patients in clinical practice. *BMJ* 2017;359:j4218.
- [34] Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014;94:291-309.
- [35] Van Maurik IS, Visser LNC, Pel-Littel RE, van Buchem MM, Zwan MD, Kunneman M, et al. Development and usability of ADappt – an online tool to support clinicians, patients and caregivers in the diagnosis of mild cognitive impairment and Alzheimer's disease. *JMIR Formative Research* 2019;3:e13417.
- [36] Feldman-Stewart D, Brennenstuhl S, Brundage MD, Roques T. An explicit values clarification task: development and validation. *Patient Educ Couns* 2006;63:350-6.
- [37] Brandes K, Linn AJ, Butow PN, van Weert JC. The characteristics and effectiveness of question prompt list interventions in oncology: a systematic review of the literature. *Psychooncology* 2015;24:245-52.
- [38] Stacey D, Legare F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:CD001431.