

## RESEARCH ARTICLE

# What patients want to know, and what we actually tell them: The ABIDE project

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## Abstract

**Background:** We studied to what degree and at whose initiative 25 informational topics, formerly identified as important, are discussed in diagnostic consultations.

**Methods:** Audio recordings of clinician–patient consultations of 71 patients and 32 clinicians, collected in eight Dutch memory clinics, were independently content-coded by two coders. The coding scheme encompassed 25 informational topics.

**Results:** Approximately half ( $Mdn = 12$ ) of the 25 topics were discussed per patient during the diagnostic process, with a higher frequency among individuals receiving a dementia diagnosis ( $Mdn = 14$ ) compared to others ( $Mdn = 11$ ). Individual topics ranged from being discussed with 2/71 (3%) to 70/71 (99%) of patients. Patients and/or care partners rarely initiated topic discussion (10%). When they did, they often enquired about one of the least frequently addressed topics.

**Conclusion:** Most patients received information on approximately half of the important informational topics. Providing the topic list to patients and care partners beforehand could allow consultation preparation and stimulate participation.

## KEYWORDS

diagnostic process, informational needs, information provision, informative topics, memory clinics

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## 1 | BACKGROUND

Increasingly more and new diagnostic options become available for Alzheimer's disease (AD) and other dementias, allowing for an earlier diagnosis.<sup>1-5</sup> As a result, the amount of information to be communicated to patients is increasing as well.

With no cure available, early diagnosis primarily informs patients about the cause and prognosis of their symptoms, and where applicable about symptom management and health-care options. With this knowledge, patients, as well as their care partners, can prepare for their future, including timely access to appropriate care.<sup>6-8</sup> Additionally, this information helps to manage patients' expectations regarding the diagnostic process. Patient expectations have consistently been shown to influence relevant patient outcomes, such as experienced treatment side effects or hospital stay duration after surgery.<sup>9-15</sup> Realistic expectations and improved understanding of the diagnostic process and its potential outcomes, help patients prepare for, and cope with, a negative outcome.<sup>2,16</sup> In addition, adequate information reduces uncertainty during the diagnostic process and may provide patients with an increased sense of control over what follows after a diagnosis. Moreover, information about the diagnostic process is a prerequisite for involving patients in decision making regarding diagnostic testing, ie, shared decision making (SDM).<sup>17,18</sup>

Although effective information provision during the diagnostic process is important, our previous studies revealed that patients and care partners express a need for more information, particularly regarding the future, ie, the patient's prognosis.<sup>6-8</sup>

To identify which informational topics are most relevant, we formerly conducted the ABIDE Delphi study.<sup>5</sup> All three stakeholder groups of patients, care partners, and clinicians identified 17 topics as highly relevant (consensus topics). Eight additional topics were identified as highly relevant in one or two, but not all three, groups (dissensus topics). The 25 topics represent information regarding (1) diagnostic testing (eg, information regarding the goal of a test, or the clinicians' considerations why a test should [not] be done), (2) diagnostic test-results (eg, the contribution of a test result to the diagnosis, or the certainty of the results), (3) diagnosis and prognosis (eg, the consequences of a diagnosis, or the prognosis in terms of progression or expected symptoms), and (4) practical implications or information (eg, information about the workings of the diagnostic process, or implications for patients' drivers' license).

Given that patients, care partners, and clinicians agree that these topics are essential to discuss during the diagnostic process, while simultaneously patients and care partners report unmet informational needs, we set out to obtain insight into the actual discussion of these topics in clinical practice. Therefore, this exploratory qualitative study aims to investigate (1) *how frequent* information from the list of the 25 topics is discussed in clinical practice; (2) *who* initiates the discussion of this information (ie, the patient, care partner, or clinician); and (3) *at which moment* the 25 information topics are addressed, ie, during the pre- and/or post-diagnostic test consultation.

### HIGHLIGHTS

- From patients' perspective, half of the relevant information is not addressed.
- Information about diagnostic testing and results is most frequently discussed.
- Diagnostic and prognostic information is least frequently discussed.
- Patients and care-partners rarely initiate a topic.
- When they do, it is often about diagnostic or prognostic information.

### RESEARCH IN CONTEXT

1. **Systematic review:** The authors searched for and reviewed traditional sources for literature (eg, PubMed), meeting abstracts, and presentations. Previous publications have established consistently reported unmet informational needs among patients and care partners during the diagnostic work-up for dementia, and that information provided in memory clinics varies substantially. In a previous study we identified 25 highly relevant informative topics, evaluated as such by clinicians, patients, and care partners, to be discussed during the diagnostic process in memory clinics. These relevant publications are appropriately cited.
2. **Interpretation:** Content-coded audio-recorded consultations of 71 patients seen by 32 clinicians, showed (a) to what degree the 25 topics are actually discussed; (b) at whose initiative, ie, the clinician, patient, or care partner; and (c) when these topics are discussed during the diagnostic process.
3. **Future directions:** The results reported on in this article can be used in clinical practice to improve information provision during the diagnostic process, and prepare and educate patients and care partners. Further, the results generate new hypotheses on examining benefits and disadvantages of providing information on all relevant topics. Examples include (a) the potential role of the topic list in stimulating more active patient/care partner participation, or (b) the effects of information provided on the topics in the topic list on patients' and care partners' satisfaction, trust in the clinician, experienced uncertainty and anxiety, or their preparedness for the future.

## 2 | METHODS

### 2.1 | Design

This observational study was part of the ABIDE project, designed to translate scientific knowledge on biomarkers for AD to everyday diagnostic practice.<sup>19</sup> For the current study we took the topic list resulting from the ABIDE Delphi study as a starting point,<sup>5</sup> and used audio recordings of the ABIDE observational study<sup>7</sup> to assess the actual discussion of the generated topics using a qualitative framework.<sup>20–22</sup> The audio recordings from the latter study comprise pre- and post-diagnostic testing clinician–patient consultations, recorded during the routine diagnostic work-up in eight Dutch memory clinics. Participating memory clinics varied in their diagnostic set-ups (eg, a diagnostic trajectory consisting of one screening day with multiple tests on a single day, versus a diagnostic trajectory with one or two diagnostic tests at a time). In the participating memory clinics, all clinicians involved in patient consultations were eligible for participation. The ABIDE observational study (audio recordings) was performed prior to the Delphi study. Thus, while some clinicians may have participated in both studies, they could not have been familiar with Delphi study results prior to the audio recordings. All memory clinic patients (N = 136) and their care partners were eligible for participation. For the current study, patients were included if complete audio recordings were present for their pre-, as well as their post-diagnostic test consultations. The resulting sample consists of audio recordings of 71 patients and 69 care partners, of 32 clinicians, in eight participating memory clinics. For the 71 patients, the sample consisted of 102 pre-test, and 72 post-test audio recordings. In the event of multiple pre- or post-test consultations for a single patient, consultations were considered one. To explore the relationship between diagnosis and amount of topics addressed, we compared patients with a dementia diagnosis and a non-dementia diagnosis. Non-dementia diagnosis included; cognitively normal patients, patients with mild cognitive impairment (MCI), unclear diagnosis, postponed diagnosis, psychiatric diagnosis, or other neurological diagnoses.

All participants provided written informed consent, and the board of the Medical Ethics Committee of Amsterdam UMC, location Academic Medical Center Amsterdam, reviewed and approved this study.

### 2.2 | Coding scheme development

Using directed qualitative content analysis,<sup>20–22</sup> a study-specific coding scheme was developed to categorize the content of the audiotaped consultations. The items for the coding scheme were determined in advance, and based on the topic list identified in the ABIDE Delphi study.<sup>5</sup> The core of the coding scheme was formed by the 25 informational topics (Figure 1). Of the 25 topics, 17 topics were deemed extremely important by clinicians, patients, and care partners (consensus topics), and eight topics by one or two, but not all three groups (dissensus topics; see Figure 1). For each of the 25 topics, the coding scheme assessed (1) whether a topic was discussed in clinical practice

(occurrence [yes/no] per patient), (2) who initiated the discussion (first to introduce the topic, either by remark or question: the clinician, the patient, or care partner), and (3) at which moment (pre- and/or post-diagnostic testing consultation). To code who initiated the discussion, patient and care partner were coded as one, because it was difficult to determine reliably from audio recordings whether the patient or the care partner was speaking. The coding scheme was further optimized in an iterative procedure, consisting of four iterations, making use of audio-recorded consultations of 20 patients not included in the current dataset. This procedure was designed to simultaneously train the two coders in using the coding scheme, as well as adapt the coding scheme after each iteration where necessary.

### 2.3 | Data analysis

To ensure reliability, all audio-recorded consultations were independently content-coded by two coders (ADF and RL), using the aforementioned coding scheme. Next, the coders compared codes and discussed differences until consensus was achieved on all codes.

Data were statistically analyzed using version 25.0 of SPSS for Windows. Descriptive statistics were used to report on the sample characteristics and answer research questions. For each information topic, frequencies are reported: (1) with how many of the 71 patients this topic was addressed; (2) how often a clinician, or patient/care partner took the initiative for discussion of the topic; and (3) whether it was addressed during a pre- and/or post-diagnostic test consultation. To explore the relationship between diagnosis and number of topics addressed, we used a Mann-Whitney U test and chi-squared or Fisher's exact test where appropriate.

## 3 | RESULTS

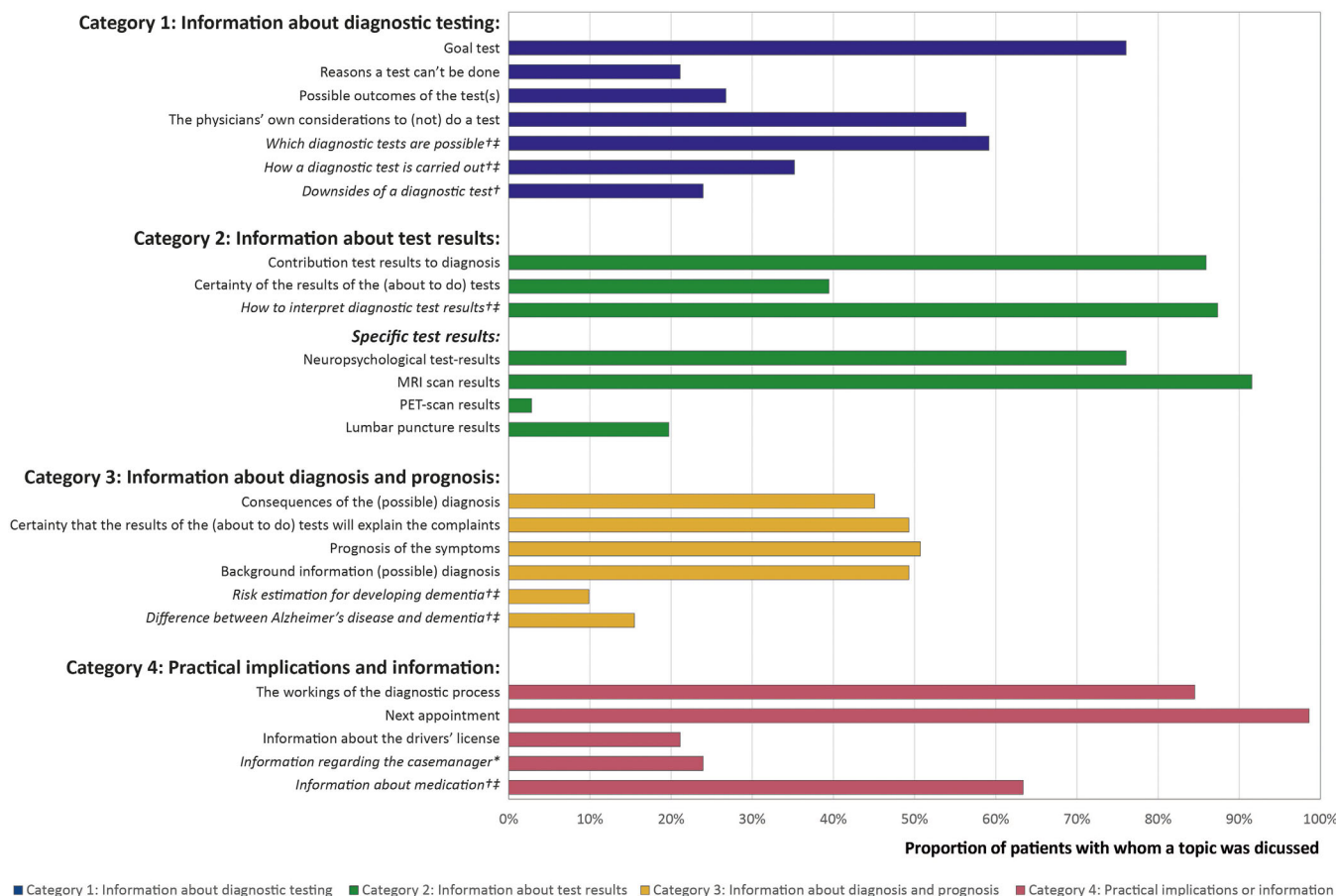
### 3.1 | Sample characteristics

Characteristics of participating patients, care partners, and clinicians are shown in Table 1. Pre-test consultations lasted an average of 48 minutes (standard deviation [SD] = 24), and post-testing consultations 19 minutes (SD = 12). During pre-testing consultations, 69 of the 71 patients (97%) were accompanied by a care partner, and 67 of the 71 patients (94%) were accompanied during the post-testing consultations.

### 3.2 | Discussion of informational topics

For each of the 25 topics, the frequency of topic discussion is presented in Figure 1 (ie, the proportion of patients with whom it was discussed). Half (*Mdn* = 9, range 2–15) of the 17 consensus topics were discussed with individual patients during the entire diagnostic process, and approximately one third (*Mdn* = 3, range 0–6) of the eight dissensus topics. Overall, this means that 12 of the 25 informational

## Proportion of patients with whom a topic was discussed in clinical practice



**FIGURE 1** How often a topic was addressed: the proportion of patients with whom a topic was discussed in clinical practice. The topics in italics are the eight topics on which we did not reach consensus among all three groups of stakeholders in the ABIDE Delphi study, ie, these “dissensus” topics were considered important by one or two of these groups; \*Clinicians evaluated this topic as more important than patients or care partners; †Patients evaluated this topic as more important than clinicians; ‡Care partners evaluated this topic as more important than clinicians.<sup>5</sup>

topics are addressed per patient. Individual topics ranged from being discussed with 2/71 (3%, the topic “PET [positron emission tomography] scan results”) to 70/71 (99%, the topic “Next appointment”) of the patients.

A number of informational topics were discussed with more than three quarters of the patients at some point during the diagnostic process. These topics were part of three of the four subcategories, and included for example the goal of a test (category “information about diagnostic testing”), how to interpret test results or their contribution to the diagnosis (category “information about test results”), and what to expect during the diagnostic process (category “practical implications and information”). Topics in the category “information about test results” were discussed most frequently ( $Mdn = 4$ , range 2–6). Of note, the topics regarding the discussion of a specific test result, such as the PET scan or lumbar puncture results, are only relevant to patients who underwent the specific diagnostic tests. However, available medical data were limited, as this study was not a medical record study. As a result, presented percentages are in relation to the entire patient group, not in relation to the patients who underwent the diagnostic

tests. Therefore, the resulting percentages for these four topics may be an underestimation.

Topics in the category “information about diagnosis and prognosis” were discussed least frequently ( $Mdn = 2$ , range 0–6), and these topics were never discussed in more than half of the patients. Within this category, the topics “difference between Alzheimer’s disease and dementia” (11/71, 15%), and “risk estimation for developing dementia” (7/71, 10%) were discussed least often. These were both topics deemed highly relevant by patients and care partners, but not by clinicians in the original Delphi study.

Further, we compared diagnostic consultations of patients with dementia to non-dementia diagnoses. A higher number of informational topics were addressed with patients who received a dementia diagnosis ( $Mdn = 14$ ), compared to patients who received a non-dementia diagnosis ( $Mdn = 11$ ; Mann-Whitney  $U = 857,5$   $P$ -value = .003). This result was driven by the informational topics “consequences of a diagnosis,” “background of a diagnosis,” “drivers’ license,” “medication,” and “information about a case manager” being more frequently discussed with dementia patients (Table A.1 in supporting

**TABLE 1** Participant characteristics

Characteristics	Patients	Care partners	Clinicians
N	71	69 <sup>a</sup>	32
Age	70 (± 10) range = 43-90	63 (± 11) range = 35-81	43 (± 12) range = 25-66
Female	32/71 (45%)	40/57 (70%)	11/32 (32%)
Education level <sup>b</sup>			
Low	19 (27%)	11 (19%)	n.a.
Medium	23 (32%)	26 (46%)	n.a.
High	18 (25%)	20 (35%)	n.a.
Missing	11 (16%)	0 (0%)	n.a.
Diagnosis <sup>c</sup>			
Dementia	29 (41%)	n.a.	n.a.
Non-dementia	42 (49%)	n.a.	n.a.
Relation to patient			
Partner	n.a.	43 (61%)	n.a.
Sibling	n.a.	4 (6%)	n.a.
Daughter-/Son (in-law)	n.a.	8 (11%)	n.a.
Other	n.a.	3 (4%)	n.a.
Specialization			
Neurologist	n.a.	n.a.	16 (50%)
Geriatrician	n.a.	n.a.	8 (25%)
Other (eg, resident or specialist nurse)	n.a.	n.a.	8 (25%)
Work experience (y)	n.a.	n.a.	8 (± 7)
Hospitals (N = 8)			
Academic	15 (21%)	n.a.	12 (38%)
Local	56 (79%)	n.a.	20 (63%)

<sup>a</sup>Data available for 57 of the 69 care-partners.

<sup>b</sup>Based on the Verhage classification;<sup>37</sup> "Low" = none to a finished low-level secondary education; "medium" = finished average-level secondary education; and "high" = finished high level secondary education or university degree.

<sup>c</sup>Based on medical record data.<sup>7</sup>

information). Of note, the topic "risk estimation for developing dementia" was not discussed more frequently with patients who received a non-dementia diagnosis.

No differences were found in number of topics discussed for other demographic factors in the current sample (ie, sex, care partner relation, education level).

### 3.3 | Initiator of addressing information topic

Discussion of almost all topics was rarely initiated by patients or care partners (10%; Figure 2). For individual topics, this ranged from 0% of the time ("neuropsychological," "lumbar puncture," and "PET-scan test results"), to 36% of the time ("difference between Alzheimer's disease and dementia"). When patients or care partners did initiate the discus-

sion, this was most frequently with regard to aspects of diagnosis and prognosis, such as "prognosis of the symptoms," or "difference between Alzheimer's disease and dementia." Of note, as can be seen in Figure 1, most of the topics on which patients/caregivers initiated a conversation were relatively infrequently discussed overall. Further, many of these were dissensus topics evaluated as very important by patients and care partners in the original Delphi study, but not by clinicians.<sup>5</sup>

### 3.4 | Moment of providing information

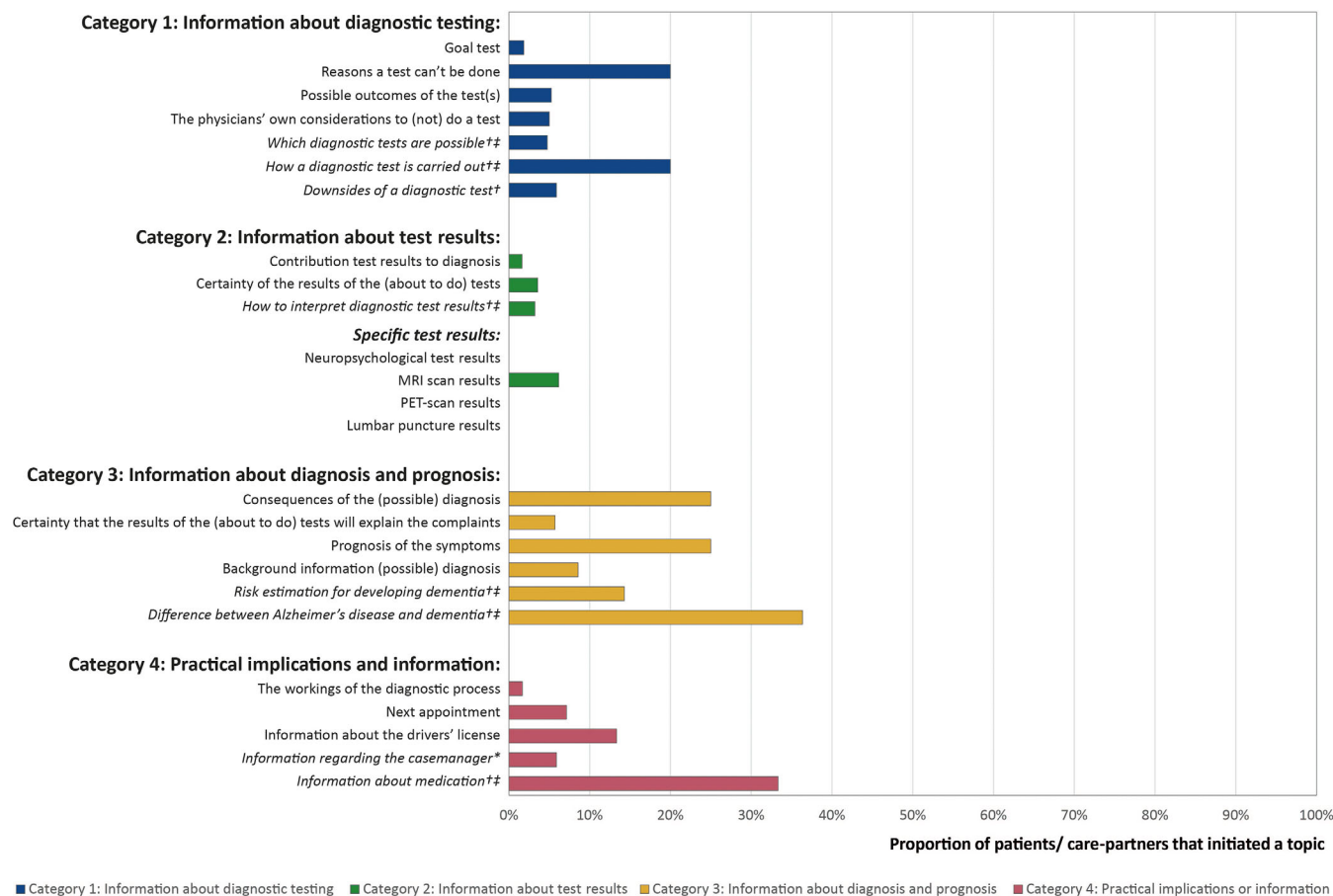
Figure 3 presents whether information was discussed during (1) a pre-diagnostic test consultation, (2) a post-diagnostic test consultation, or (3) both the pre- and post-diagnostic test consultations. The timing of discussions as observed in the current study is primarily concordant with the optimal moment as established in the original Delphi study.<sup>5</sup> During pre-diagnostic test consultations informational topics (*Mdn* = 5, range 0–12) covered foremost information regarding diagnostic testing. During post-diagnostic test consultations topics (*Mdn* = 9, range 3–19) primarily concerned information regarding test results, diagnosis and prognosis, and practical information. Over half of the discussed topics (15 of 25), were discussed both before and after diagnostic testing (eg, information was repeated or expanded upon).

## 4 | DISCUSSION

With this empirical study we gained insight into the actual provision of information in memory clinic consultations. More specifically, this study shows that approximately half of the 25 informational topics are discussed within diagnostic trajectories of individual patients. The frequency with which individual topics are discussed with patients in clinician-patient consultations, ranges from almost always to only rarely. In addition, patients and care partners rarely initiated discussion of an informational topic, leaving the initiative to clinicians. When they did initiate the discussion, they did so most often for topics that are overall discussed the least frequently, such as "the difference between AD and dementia." Further, while approximately half of the 17 informational consensus topics are regularly discussed with patients, only three of the eight dissensus topics are regularly discussed, ie possible diagnostic tests, interpretation test results, and medication. The remaining five are discussed with less than half of the patients. Nevertheless, these topics have previously been reported as informational needs by patients and care partners.<sup>5,6,8</sup> In the current study their importance is further emphasized by patients and care partners enquiring about these topics, suggesting the eight dissensus topics are of equal importance to the 17 consensus topics. Third, as the timing of discussions is generally primarily concordant with the optimal moment as identified in our original Delphi study, this implies that clinicians intuitively find the right timing for introducing specific information during the diagnostic trajectory.

While we see in clinical practice that half of the informative topics are often addressed, these results also imply that from an

## Proportion of patients/ care partners that initiated a topic in clinical practice



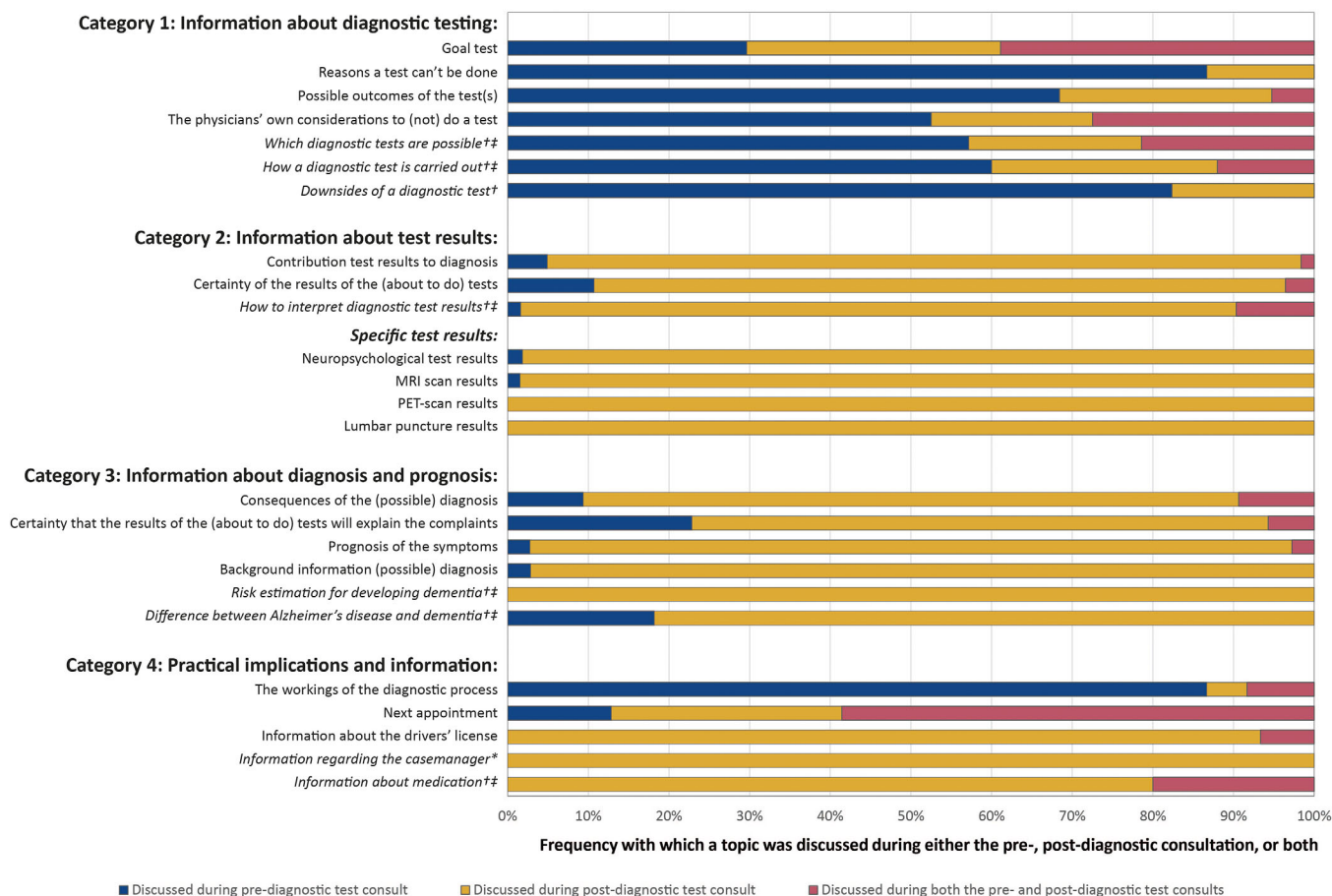
**FIGURE 2** Who initiated discussion of the topic: proportion of clinician, or patient and care partners that initiated the discussion of individual topics. The topics in italics are the eight topics on which we did not reach consensus among all three groups of stakeholders in the ABIDE Delphi study, ie, these “dissensus” topics were considered important by one or two of these groups; <sup>†</sup>Clinicians evaluated this topic as more important than patients or care partners; <sup>‡</sup>Patients evaluated this topic as more important than clinicians; <sup>‡</sup>Care partners evaluated this topic as more important than clinicians.<sup>5</sup> Proportions reflect the number of times a patient or care partner initiated the topic, in relation to how often the topic was discussed overall. The remaining proportion was initiated by clinicians. Patient or care partner initiative overall is low, but relatively high on the majority of the dissensus topics.

individual patient's perspective half of the relevant topics are *not* addressed. Closer inspection of infrequently discussed topics reveals these regard the informational categories “Information about diagnostic testing” (eg, possible outcome[s] of a test, or how a test is conducted), and “Information about diagnosis and prognosis” (eg, consequences of diagnosis, prognosis of the symptoms, risk estimation for developing dementia, or the difference between AD and dementia). This finding supports previously reported unmet informational needs among patients and care partners,<sup>6,8</sup> because information relevant to patients and care partners appears to remain undiscussed. Our current study provides insight into which specific informational topics may be at the core of the unmet informational needs.

Furthermore, the variation with which topics are discussed suggests it is a subset of topics that require more attention in clinical practice. This variation may partially be explained by the differences between patients, eg, in symptom severity or personal circumstances. As a result, not all topics are equally relevant to all patients, and topics may

therefore be addressed less frequently. In fact, our findings support this notion, and show that certain topics are discussed more frequently with patients who receive a dementia diagnosis compared to patients who do not; particularly topics regarding practical implications, such as information about a drivers' license and medication. Nevertheless, most topics among the frequently discussed topics are addressed regardless of diagnosis. It could be that patients with non-dementia diagnoses (eg, MCI) or their care partners already have questions on these topics, as they may become relevant in the future. Likewise, certain topics may be more relevant to patients with a non-dementia diagnosis, in particular “risk estimation for developing dementia.” One might expect this topic to be addressed more often with patients who receive a non-dementia diagnosis such as MCI, because they are at increased risk for developing dementia.<sup>23,24</sup> However, this is not supported by our findings, as this topic remains largely undiscussed regardless of diagnosis. Although the current qualitative approach allowed us to take this first, valuable step in investigating patient

### When a topic was discussed: during the pre-, or post-diagnostic test consultation, or both



**FIGURE 3** When a topic was addressed during the diagnostic process: frequency with which a topic was addressed in the pre-, the post-diagnostic test consultation, or both. The topics in italics are the eight topics on which we did not reach consensus among all three groups of stakeholders in the ABIDE Delphi study, ie, these “dissensus” topics were considered important by one or two of these groups; † Clinicians evaluated this topic as more important than patients or care partners; ‡ Patients evaluated this topic as more important than clinicians; ‡ Care partners evaluated this topic as more important than clinicians.<sup>5</sup>

differences in information provision, further research is needed using a quantitative approach. Nevertheless, patient differences only provide a partial explanation, in particular as it only applies to a selection of the 25 informational topics. Other infrequently discussed topics, such as “possible outcomes of a test,” apply to all patients undergoing a diagnostic trajectory.

Alternatively, clinicians may experience difficulty with addressing all topics during the diagnostic process. While this may be partially explained by time restrictions for consultations, it may also result from the clinicians' concern for their patient's well-being. Prior studies, primarily in other fields, have noted that clinicians struggle with providing diagnostic, or prognostic, information.<sup>25–29</sup> For example, clinicians may be concerned that discussing specifics about diagnostic testing, diagnosis, or prognosis may be too complex, or emotionally burdensome for their patients. This is in line with a previous study by Visser et al. showing clinicians are inclined to balance a potentially negative outcome in MCI patients by emphasizing the possibility of a good outcome, thus fostering hope in patients.<sup>30</sup> A more straightforward explanation may

be that clinicians are unaware of patients' and their care partners' informational needs. Similarly, perhaps clinicians who want to meet their patients' and care partners' informational needs struggle with simultaneously preventing an information overload. Enquiring after patients' or care partners' informational needs and preferences, in particular when addressing diagnostic or prognostic informational topics, might provide a solution to both aforementioned issues.

Further, development of clear and evidence-based guidelines on communicating diagnostic and prognostic information in the memory clinic setting may reduce barriers clinicians experience in communicating these topics. Moreover, informing a patient about these topics not only serves the goal of information provision, it allows the clinician to enquire about, and include, the patients' views on the various options in the decision-making process, as well as to provide more individualized information. Information about diagnostic tests, but also about diagnosis or prognosis, may be helpful in managing patients' expectations regarding the diagnostic trajectory, and all that it entails. With no treatment available, managing expectations of patients visiting a

memory clinic is of great importance, and may help them cope better with a negative outcome.<sup>2,16</sup> In addition, it provides patients and their care partners with a framework for their future.<sup>2,31,32</sup> Not only does it help patients and care partners to better understand a patients' symptoms as they progress, it allows them to plan for their future, and arrange for appropriate care, as well as do advanced care planning. Perhaps more importantly, our findings are in line with previous research that suggests patients and care partners want this information.<sup>5,6,8,33</sup>

Our results show that patients and care partners rarely initiate discussion of an informational topic, in spite of the value they place on these informational topics. Naturally, patients may vary in their expectations of the diagnostic process, their wish to be involved, and the extent to which they want information during the diagnostic process. Several factors may contribute to patients' or care partners' lack of initiative. First, patients and care partners might be overwhelmed with the amount of the information provided. Second, previous literature reports certain person-characteristics may prove barriers to patient participation, such as level of education, illness severity, (un)certainly, or shyness.<sup>34,35</sup> Third, factors related to the clinician or clinical setting are reported to influence patient participation as well (eg, communication style or time available).<sup>34,35</sup> Such factors are equally applicable to patients visiting memory clinics. Finally, the information may be too complicated, particularly in light of patients' cognitive problems. If so, this may hinder their ability to ask (follow-up) questions or result in shame, preventing their participation in meaningful interactive clinician-patient communication. Of note, in the rare situations that patients and care partners initiated the discussion of an informational topic, this pertained most often to topics otherwise seldomly discussed. This appears to further substantiate the importance of these topics to patients and care partners. Given the success of interventions aimed at improving patient initiative in fields such as oncology,<sup>36</sup> future work should examine possible benefits of such interventions in memory clinic populations.

The fact that half of the relevant topics are addressed in a timely manner during consultations, supports the feasibility of addressing items from the topic list in diagnostic consultations. Previously, four topics were identified as suitable to be addressed by a different clinician, sometime after having received a diagnosis ("consequences of a diagnosis," "prognosis of the symptoms," "driver's license," and "casemanager")<sup>5</sup>. Here, we see that these topics are addressed during the post-diagnostic test consultation. However, patients often see more than one clinician during their diagnostic trajectory, and one clinician may assume another will address one or several of the relevant topics. Consequently, there is a risk of topics remaining undiscussed. Clinics might use the results of the current study to consider which information should be provided by whom during the diagnostic trajectory, thus optimizing their clinics' information provision, and ensuring questions are answered. Further, more active patient and care partner involvement may reduce that risk. Providing patients and care partners with a question prompt list, printed materials, or an online information source prior to attending a consultation may prove beneficial to increasing patient involvement.<sup>38,39</sup> Thus, this may result in improved individualized information provision, as patients and care partners are

able to ask questions on topics pertinent to their situation and preferences. Nevertheless, we don't yet know if providing information for all (relevant) informational topics truly benefits patients, as evaluating the impact of discussing the informational topics was beyond the scope of the current study. In addition, current literature proposes diagnostic and prognostic information may help reduce health crises and required health care, by aiding patients and care partners in their preparation for the future.<sup>2,6</sup> Future research should examine potential benefits or disadvantages of addressing all of the informational topics, such as effects on comprehension of a diagnosis, experienced anxiety, satisfaction with the information and/or clinician, and possible long-term effects.

A strength of this study is that the meticulously analyzed, audio-recorded consultations originate from a multi-center study, including a heterogeneous group of clinicians and patients. The results are therefore applicable to memory clinics with different diagnostic set-ups. Further, reliability of the coding was ensured by careful development of a study-dedicated coding scheme, in addition to two coders independently coding all audio recordings. However, there are also some limitations to our findings. Due to limited available medical records data, we were unable to provide percentages on how often specific diagnostic test results were discussed, in relation to the amount of patients who underwent these diagnostic tests. Further, we did not evaluate *how* the various topics were addressed, ie, the quality of the clinician-patient interaction. Nevertheless, it may be the quality that ultimately determines whether a patient and/or care partner benefitted from a specific topic discussion. Evaluating the quality of the clinician-patient interaction would require a more in-depth look at various conversational elements, such as a discourse analysis, the content or duration of a topic discussion, effects of clinician-patient symmetry with this particular patient population, effects of nonverbal characteristics (eg, turn-taking patterns, eye contact), effects of consultation time, or the use and effectiveness of various communicative strategies (eg, patient-centeredness). Further, all data pertain to Dutch memory clinics. As such, they may be less generalizable to other countries, as issues not discussed here might be considered equally valuable in other countries or cultures. It would therefore be a good next step to repeat our entire Delphi study, including the observation of actual consultations, in other countries. Of note, many of the topics reported here are applicable to the diagnostic process in general, regardless of the setting. Therefore, the findings of our study may apply to memory clinics in other cultural contexts as well.

## 5 | CONCLUSIONS

In conclusion, patients received information on approximately half of the topics from the topic list, previously identified as important to discuss during the diagnostic process. Overall, informational topics regarding test results were discussed most frequently, whereas information regarding diagnostic and prognostic information received far less attention. Facilitating the discussion of these important informational topics is therefore imperative, eg, by providing clinicians,



and patients and their care partners, with the topic list prior to their visit.

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## CONFLICTS OF INTEREST

The authors have declared no conflicts of interest for this article. The funding sources had no involvement in the study design; data collection, analysis, and interpretation; in writing the article; nor in the decision to submit this article for publication.

## REFERENCES

- Dubois B, Hampel H, Feldman HH, et al. Preclinical Alzheimer's disease: definition, natural history, and diagnostic criteria. *Alzheimers Dement*. 2016;12(3):292-323.
- 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(3):617-631.
- Mckhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011;7(3):263-269.
- Scheltens P, Blennow K, Breteler MMB, et al. Alzheimer's disease. *Lancet North Am Ed*. 2016;388(10043):505-517.
- Fruijtier AD, Visser LNC, Van Maurik IS, et al. ABIDE Delphi study: topics to discuss in diagnostic consultations in memory clinics. *Alzheimers Res Ther*. 2019;11(1).
- Kunneman M, Pel-Littel R, Bouwman FH, 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(3):314-322.
- Visser LNC, Kunneman M, Murugesu L, et al. Clinician-patient communication during the diagnostic workup: the ABIDE project. *Alzheimers Dement (Amst)*. 2019;11:520-528.
- Whitlatch CJ, Orsulic-Jeras S. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *Gerontologist*. 2018;58(suppl\_1):S58-S73.
- Kalauokalani D, Cherkin DC, Sherman KJ, Koepsell TD, Deyo RA. Lessons from a trial of acupuncture and massage for low back pain. Patient expectations and treatment effects. *Spine*. 2001;26(13):1418-1424.
- Roscoe JA, Bushnow P, Morrow GR, et al. Patient expectation is a strong predictor of severe nausea after chemotherapy: a University of Rochester Community Clinical Oncology Program study of patients with breast carcinoma. *Cancer*. 2004;101(11):2701-2708.
- Marschall-Kehrel D, Roberts RG, Brubaker L. Patient-reported outcomes in overactive bladder: the influence of perception of condition and expectation for treatment benefit. *Urology*. 2006;68(2 Suppl):29-37.
- Halawi MJ, Vovos TJ, Green CL, et al. Patient expectation is the most important predictor of discharge destination after primary total joint arthroplasty. *J Arthroplasty*. 2015;30(4):539-542.
- Halawi MJ, Vovos TJ, Green CL, Wellman SS, Attarian DE, Bolognesi MP. Preoperative pain level and patient expectation predict hospital length of stay after total hip arthroplasty. *J Arthroplasty*. 2015;30(4):555-558.
- Laferton JAC, Kube T, Salzmann S, Auer CJ, Shedden-Mora MC. Patients' expectations regarding medical treatment: a critical review of concepts and their assessment. *Front Psychol*. 2017;8:233.
- Wiering B, De Boer D, Delnoij D. Meeting patient expectations: patient expectations and recovery after hip or knee surgery. *Musculoskelet Surg*. 2018;102(3):231-240.
- Ahalt C, Walter LC, Yourman L, Eng C, Pérez-Stable EJ, Smith AK. Knowing is better": preferences of diverse older adults for discussing prognosis. *J Gen Intern Med*. 2012;27(5):568-575.
- Stiggelbout AM, Weijden TVD, Wit MPTD, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ*. 2012;344:e256.
- Elwyn G, Frosch D, Thomson R, et al. Shared Decision Making: a Model for Clinical Practice. *J Gen Intern Med*. 2012;27(10):1361-1367.
- Wilde A, Maurik IS, Kunneman M, et al. Alzheimer's biomarkers in daily practice (ABIDE) project: rationale and design. *Alzheimers Dement (Amst)*. 2017;6:143-151.
- Assaroudi A, Heshmati Nabavi F, Armat MR, Ebadi A, Vaismoradi M. Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. *J Res Nurs*. 2018;23(1):42-55.
- Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-115.
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
- Albert MS, Dekosky ST, Dickson D, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011;7(3):270-279.
- Van Maurik IS, Zwan MD, Tijms BM, et al. Interpreting biomarker results in individual patients with mild cognitive impairment in the Alzheimer's Biomarkers in Daily Practice (ABIDE) Project. *JAMA Neurol*. 2017;74(12):1481-1491.
- Canada PHAo, Conference Report: National Dementia Conference: Inspiring and Informing a National Dementia Strategy for Canada. 2018.
- Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MHN. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol*. 2005;16(7):1005-1053.
- Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med*. 2007(21):507-517.
- Thai JN, Walter LC, Eng C, Smith AK. Every patient is an individual: clinicians balance individual factors when discussing prognosis with diverse frail elderly adults. *J Am Geriatr Soc*. 2013;61(2):264-269.
- Schoenborn NL, Bowman TL, Cayea D, Pollack CE, Feeser S, Boyd C. Primary care practitioners' views on incorporating long-term prognosis in the care of older adults. *JAMA Intern Med*. 2016;176(5):671-678.
- Visser PJ, Wolf H, Frisoni G, Gertz H-J. Disclosure of Alzheimer's disease biomarker status in subjects with mild cognitive impairment. *Biomark Med*. 2012;6(4):365-368.

31. Garand L, Dew MA, Lingler JH, Dekosky ST. Incidence and predictors of advance care planning among persons with cognitive impairment. *Am J Geriatr Psychiatry*. 2011;19(8):712-720.
32. Holloway RG, Gramling R, Kelly AG. Estimating and communicating prognosis in advanced neurologic disease. *Neurology*. 2013;80:764-772.
33. Moré JM, Lang-Brown S, Romo RD, Lee SJ, Sudore R, Smith AK. "Planting the Seed": perceived Benefits of and Strategies for Discussing Long-Term Prognosis with Older Adults. *J Am Geriatr Soc*. 2018;66(12):2367-2371.
34. Noordman J, Driesenaar JA, Henselmans I, Verboom J, Heijmans M, Van Dulmen S. Patient participation during oncological encounters: barriers and need for supportive interventions experienced by elderly cancer patients. *Patient Educ Couns*. 2017;100(12):2262-2268.
35. 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(3):291-309.
36. D'agostino TA, Atkinson TM, Latella LE, et al. Promoting patient participation in healthcare interactions through communication skills training: a systematic review. *Patient Educ Couns*. 2017;100(7):1247-1257.
37. Verhage F. Intelligence and Age: Research Among the Dutch Aged 12 to 77 [in Dutch]. 1964, Assen, the Netherlands: van Gorcum.
38. Brandes Kim, Linn Annemiek J., Butow Phyllis N., van Weert Julia C. M.. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psycho-Oncology*. 2015;24(3):245-252. <http://doi.org/10.1002/pon.3637>.
39. Sansoni Janet E, Grootemaat Pam, Duncan Cathy. Question Prompt Lists in health consultations: A review. *Patient Education and Counseling*. 2015;98(12):1454-1464. <http://doi.org/10.1016/j.pec.2015.05.015>.

#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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