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## **Motivations of patients and their care partners for visiting a memory clinic: a qualitative study**

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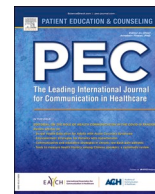
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## Motivations of patients and their care partners for visiting a memory clinic. A qualitative study

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## ABSTRACT

**Objective:** We investigated motivations of patients and care partners for their memory clinic visit, and whether these are expressed in consultations.

**Methods:** We included data from 115 patients (age  $71 \pm 11$ , 49% Female) and their care partners ( $N = 93$ ), who completed questionnaires after their first consultation with a clinician. Audio-recordings of these consultations were available from 105 patients. Motivations for visiting the clinic were content-coded as reported by patients in the questionnaire, and expressed by patients and care partners in consultations.

**Results:** Most patients reported seeking a cause for symptoms (61%) or to confirm/exclude a (dementia) diagnosis (16%), yet 19% reported another motivation: (more) information, care access, or treatment/advice. In the first consultation, about half of patients (52%) and care partners (62%) did not express their motivation(s). When both expressed a motivation, these differed in about half of dyads. A quarter of patients (23%) expressed a different/complementary motivation in the consultation, then reported in the questionnaire.

**Conclusion:** Motivations for visiting a memory clinic can be specific and multifaceted, yet are often not addressed during consultations.

**Practice implications:** We should encourage clinicians, patients, and care partners to talk about motivations for visiting the memory clinic, as a starting point to personalize (diagnostic) care.

**Abbreviations:** ABIDE, Alzheimer Biomarkers in Daily Practice; AD, Alzheimer's Disease; MCI, Mild cognitive impairment; MMSE, Mini-mental state examination; CN, Cognitively normal.

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## 1. Introduction

Currently, an estimated 55 million people are living with dementia worldwide [1]. This number is expected to grow rapidly to 150 million by 2050 due to the aging population, unless we find ways to prevent, slow or cure underlying diseases such as Alzheimer's disease [2]. New diagnostic tests are therefore developed and implemented in memory clinic practice, numerous disease-modifying drugs and lifestyle interventions are under investigation in clinical trials, and strategies to maintain brain health are promoted [3]. In all these initiatives, a personalized medicine approach is advocated to do justice to variation among humans, i.e., the tailoring of strategies to an individual to maximize the beneficial effects and minimize potential harms [4].

Personalization can be based on a person's risk profile in terms of genetics, biomarkers, or lifestyle traits, yet in the ambition to align care to better fit the situation of individual patients, personalized medicine also implies taking into account the individual's personal preferences and needs [5]. Such person-centeredness is considered the hallmark of high quality care, and attuning to the individual's needs could be beneficial in terms of improving patient outcomes such as their quality of life, enhancing patient and care partner satisfaction and the relation with healthcare providers [6]. In addition, from the healthcare provider perspective, the person-centered approach could reduce stress and improve job satisfaction [6]. Taking the personal preferences and needs of patients and their care partners into account, starts with establishing their motivation(s) for embarking on a diagnostic trajectory in a memory clinic.

Moreover, recognizing an individual's and their care-partner's personal motivations and expectations regarding the diagnostic trajectory and its potential outcome can shape the diagnostic trajectory, resulting in a customized and efficient diagnostic work-up. The increasing number of biomarker tests available in the clinical setting and the emergence of disease-modifying drugs, which come with their own set of benefits and harms [7], are likely to further increase the variation in individual expectations, needs and preferences. Thus, highlighting the relevance of exploring the motivations of patients and their care partners at the start of the diagnostic trajectory and thereby engaging them in their own healthcare, including medical decisions [8].

We know from previous research in the oncological setting that motivations, expectations and preferences are often not addressed or expressed in clinical consultations [9]. In the memory clinic context such insight is still lacking. The aim of this study was to investigate the motivations of patients for visiting a memory clinic, and to what extent the motivations of patients and their care partners are currently addressed during routine diagnostic consultations. In addition, we aimed to observe if patients and their care partners express similar motivations, or if complementary or different motivations exist within dyads. We used a qualitative approach for this study, since it allows for exploration of the (potentially complex) motivations as expressed by patients and their care partners.

## 2. Methods

### 2.1. Design

The qualitative data analyses for the current publication were conducted in the context of the ABOARD project, which aims to take the necessary steps to prepare for a future with personalized medicine for Alzheimer's disease (AD). Data were originally gathered as part of the ABIDE-observational study [10,11], in which we collected questionnaire data among newly-referred patients and their accompanying care partners, and audio-recorded clinician-patient consultations during the routine diagnostic work-up in memory clinics [11]. In previous publications on these data, we mainly focused on observed clinician communication behavior [11–13]. To explore and systematically classify motivations from the perspectives of patients and their care partners

for the purpose of the current publication, we took on a qualitative approach using content analysis [14]. In addition, to describe our sample, diagnostic information and data on Mini Mental State Examination (MMSE) scores were retrieved from patients' medical records. All participants provided written informed consent. The board of the Medical Ethics Committee of the Academic Medical Center in Amsterdam reviewed this study and exempted our observational research from further review by the full ethics committee.

### 2.2. Participants and procedures

Details about participant recruitment and procedures were previously published [11]. Only newly-referred patients (by a general practitioner or another medical specialist, no self-referral), seen as a part of routine memory clinic care, and their accompanying care partners were invited to participate. Patients or care partners with poor comprehension of the Dutch language and/or not able to provide informed consent (Mini Mental State Examination score <18) were not eligible. Originally, 136 memory clinic patients were included in the larger observational study. The current qualitative study included data from patients (N = 115) and their accompanying care partners (N = 95) who fully completed a questionnaire administered after their first memory clinic visit. We made audio-recordings of the initial clinician-patient consultations, i.e., during the first memory clinic visit. We only included audio-recorded data if the complete consultation was successfully recorded, which was the case for 105 of these patients. The patients were seen by 37 clinicians at 8 Dutch memory clinics, including one academic hospital, six non-academic teaching hospitals and one non-academic, non-teaching hospital.

### 2.3. Questionnaires

Patients and care partners completed a questionnaire after the first-visit consultation, which included demographic characteristics (i.e., age, gender, education level, relation to the patient). The questionnaire for patients included an open-ended question: What purpose do you have for visiting the memory clinic?

Patients and care partners additionally received the following two questions: i) For how many years have you/has the patient been experiencing symptoms? and ii) Who is worried most about your/the patient's symptoms? For the latter they could select out of four answer categories: Patient (I am/the patient is); Relative (My relative(s)/I am, or another relative is); Another physician (e.g., the GP); Someone else, namely...).

### 2.4. Qualitative content coding of open-ended question and audio-recordings

To analyze and interpret both the answers to the open-ended question and the audio-recorded consultation data, we took on a qualitative content analysis approach, i.e., a systematic classification process of coding and identifying themes or patterns [14]. A study-specific coding scheme (see Box 1) was developed based on previous work and initial audio recordings [15,16], aimed at classifying the motivations for visiting the memory clinic as i) reported by patients in the questionnaire in answer to the open-ended question, and ii) expressed by patients and/or by their care partners in the audio-recorded consultations. Here, we defined motivation as their motive or reason for visiting the memory clinic; what did they want/hope to achieve?

The research team involved in the qualitative content analyses was led by AF (PhD-student) and LNCV (senior researcher) both experienced in conducting qualitative research and with a background in psychology, and supported by RL, JvdS and AH, who were (PhD-)students trained for the purpose of this study. For the answers to open-ended question, AF and LNCV first read through all written answers and then independently coded all answers using the coding scheme.

**Box 1**

The study-specific coding scheme used to classify motivations.

**What was reported by the patient in the questionnaire in answer the open-ended question / expressed in the consultation by the patient and by the care partner as the motivation to visit the memory clinic?**

**(0) [Not reported / expressed]**

The patient reported no motivation in answer to the open-ended question / The patient (or care partner) did not express any motivation nor agreed with a statement from any of the other parties present during the consultation;

**(1) [To confirm or exclude dementia]**

The patient (or care partner) reported / expressed or agreed that he/she wants to confirm or exclude dementia;

**(2) [To find out the cause of complaints/symptoms]**

**(2a)** In explicit wording: the patient (or care partner) explicitly reported / expressed or agreed that he/she wants to find an explanation for/know the cause of the patient's complaints/symptoms, including wanting to get tested, e.g., biomarker testing for Alzheimer's disease;

**(2b)** In general terms: the patient (or care partner) reported / expressed in more vague or general terms that he/she wants to 'find clarity/certainty' or 'find out what's is going on', or agreed with such a general statement;

**(3) [To confirm other cause/diagnosis]**

The patient (or care partner) reported / expressed or agreed that he/she wants to confirm a specific cause/diagnosis other than dementia or Alzheimer's disease, e.g., *brain tumour, burn out, Parkinson*;

**(4) [Other]**

Only coded if none of the above is applicable and another motivation is explicitly reported in the questionnaire / expressed by the patient (or care partner) in the consultation, e.g., 'to find a treatment for symptoms'.

Disagreements in codes were discussed and resolved in consensus. For the audio-recordings, coders were instructed to first just listen to an audio-recording. They were trained to select one of the motivation categories for patients as well as for care partners (if present during the consultation) while listening to the audio-recordings for a second time and instructed to note all examples/quotes. All audio-recorded consultations were independently coded by AF and RL, except for consultations in the Fries dialect (N = 4) which were coded by JvdS and AH. Disagreements in codes were discussed and resolved in consensus, when necessary arbitrated by a third coder (LNCV).

For both open-ended question answers and audio-recordings, the motivations coded under the category 'Other' were further classified by LNCV and AF using an inductive approach, identifying themes based on the data. By adding such a bottom-up approach to the more directed content-analysis approach as described above, we left room for meaningful clusters of motivations to emerge from the data other than the pre-defined categories [14].

### 2.5. Medical record

We retrieved information from patients' medical records on the mini-mental state examination (MMSE) and diagnosis after conclusion of their diagnostic trajectory. Based on those data, all patients were categorized into one of four broadly-defined (syndrome) diagnostic groups [11]: (1) 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 (CN); (4) Other/Unclear.

### 2.6. Statistics

IBM SPSS statistics software and descriptive statistics were used to analyze and report characteristics of the sample, questionnaire responses and coded communication. We used a paired-sample T-test to compare reported years since first experiencing symptoms between patients and care partners, and chi-square tests to compare proportions/percentages between diagnostic groups.

## 3. Results

### 3.1. Sample descriptives

Table 1 displays characteristics of the 115 patients that completed the questionnaire. Of these individuals, 40% received a dementia diagnosis, 17% were labeled with MCI, 25% were cognitively normal, and

**Table 1**

Characteristics of patients and their accompanying care partners.

	Patients N = 115	Care partners N = 95
<b>Gender (female)</b>	56 (49%)	63 (66%)
<b>Age in years (mean<math>\pm</math>SD, range)</b>	71 $\pm$ 11, 43–91	62 $\pm$ 13, 19–86
<b>Highest level of education<sup>a</sup></b>		
1–4: primary school/lower-level vocational education	39 (34%)	17 (18%)
5–6: general secondary education	43 (37%)	41 (43%)
7: higher-level vocational/university education	27 (24%)	36 (31%)
Other	6 (5%)	1 (1%)
<b>Mini mental state examination (MMSE; mean <math>\pm</math>SD, range)<sup>b</sup></b>	26 $\pm$ 4, 12–30	
<b>Syndrome diagnosis</b>		
Dementia	46 (40%)	
MCI	20 (17%)	
Cognitively normal	29 (25%)	
Other/unclear, including 2 missings	20 (17%)	
<b>Who is most concerned about the patient's symptoms? Patient and care partner answers</b>		
Multiple answers selected <sup>c</sup>	29 (25%)	18 (19%)
Patient	40 (35%)	24 (25%)
Relative(s)	37 (32%)	43 (45%)
Another doctor (e.g., the GP)	4 (3%)	4 (4%)
Someone else	2 (2%)	3 (3%)
Not answered/blank	3 (3%)	3 (3%)

Notes. a: classification based on Verhage (1964), b: data available from 107 patients, c: participants were instructed to select one answer option, yet a substantial proportion selected more than one answer. When multiple answers were selected by patients and care partners, most often they selected the patient and relative(s).

the remaining 17% of individuals received another diagnosis or their status was (of yet) unclear at the end of this diagnostic trajectory. Patients were accompanied by a care partner in 90% (103/115) of first visits, and 95/103 care partners completed the questionnaire; two-thirds of them were spouse/partner of the patient (63/95; 66%), 22/95 (23%) were a daughter or son (in law) and 10/95 (11%) had another relation to the patient, e.g., a sibling. For 105/115 (91%) patients, audio-recordings of the first consultations were available for analysis, who were seen by 37 clinicians, i.e., 15 neurologists, 12 geriatricians and 10 other (e.g., psychiatrist, specialized nurse), 27/37 of them being female.

Patients reported to have been experiencing symptoms for 3 years on average ( $SD=6$ ); care partners reported symptoms to have been present for an average of 4 years ( $SD=7$ ) ( $t(88) = -1.856, p = .067$ ). The lower part of Table 1 displays the responses of patients and care partners to the survey question ‘Who is most concerned about the patient’s symptoms?’, highlighting that 37% of patients and 52% of care partners identify someone other than the patient as the one being *most* concerned.

### 3.2. Motivations of patients for visiting the memory clinic as written down in the questionnaire

We categorized the answers of patients to the open-ended question into categories (see Box 1 and Table 2). The majority of patients (70/115; 61%) answered that they want(ed) to find out what’s causing their symptoms or problems. For example, one patient wrote: “My memory problems... I wonder if that is age-related, or if there’s another cause? (ID-5116)”. Half of these patients (35/70) explicitly stated they wanted to find out what is causing their symptom(s), such as illustrated in the quote above. The other half of these patients (35/70) stated in more general terms that they wanted “clarity”, “certainty” or “to find out what’s wrong”, e.g., “My goal is getting clarity and knowing where I stand (ID-2106)”. Smaller proportions of patients wanted to confirm or exclude dementia (15/115; 13%) or another specific disease/diagnosis (3/115; 3%).

One in five patients (22/115; 19%) reported a motivation other than finding a cause or confirming/excluding dementia or another specific disease/diagnosis (the ‘Other’ category). Three main themes were identified within these ‘other’ motivations, patients were seeking for: (i) **(more) information**, (ii) **access to care (services)**, and (iii) **treatment or advice**. Some patients wanted (more) information about their current diagnosis: “My objective was to collect as much information as possible about dementia (ID-8105)”, or information about the future: “I want to know if I will develop dementia (ID-6114)” or “To optimally prepare for the future (ID-3114)”. Others were aiming to get a diagnosis so that they could get access to care (services), for example “To enable me taking part in day care activities two or three half-days a week (ID-2103)”. In addition, some patients were aiming for treatment or advice regarding the management of their symptoms or disease, as illustrated by the following quotes: “I want to know if we can do something about my memory problems (ID-8108)”, “To solve this problem (ID-7104)” and “To find out if my situation can be improved or stabilized (ID-2118)”.

Less often stated motivations were: “because I want to drive a car again

**Table 2**  
Motivations of patients for visiting the memory clinic – questionnaire responses.

	Full sample N = 115	Dementia N = 46	MCI N = 20	CN N = 29	Other N = 20
To confirm/exclude dementia	15 (13%)	3 (7%)	2 (10%)	9 (31%)	1 (5%)
To find cause of symptoms	70 (61%)	28 (61%)	16 (80%)	15 (52%)	11 (55%)
To confirm/exclude another diagnosis	3 (3%)	1 (2%)	2 (10%)	2 (7%)	0
Other	22 (19%)	11 (24%)	0	3 (10%)	6 (30%)
Not answered/expressed	5 (4%)	3 (1%)	0	0	2 (10%)

*Notes.* Comparing proportions between diagnostic groups using a chi-square test was only possible for the category ‘to find the cause of symptoms’, since frequencies were not consistently high enough in other categories. Although the proportion of patients who wanted to find a cause of symptoms (versus all other motivations) was the highest in the group with MCI (80%), compared to dementia (61%), cognitively normal (52%), and other/unclear (55%), the proportions did not differ significantly between groups ( $X^2(3, 115) = 4.38, p = .22$ )

(ID-5125)”, “to evaluate use of medicines (ID-1106)”, and “to express my feelings (ID-8102)”. Moreover, some patients reported that from their perspective, visiting the clinic did not have a purpose, e.g., “For me this consultation wasn’t necessary (ID-2104)” or “None. My daughter took the initiative (ID-5127)”. Of note, only a few patients left this open-ended survey question blank/unanswered (5/115; 4%), indicating that most patients were able to specify why they visited the memory clinic.

### 3.3. Motivations expressed by patients and care partners in the audio-recorded first consultation

Table 3 displays motivations to visit a memory clinic as expressed by patients and care partners in the first consultation with their clinician (see Box 1 for the coding scheme). Approximately half of the patients (55/105; 52%) did not voice what they wanted to achieve at the memory clinic. This percentage did not differ between diagnostic groups ( $X^2(3, 105) = 2.60, p = .46$ ; Dementia 55%, MCI 65%, Cognitively normal 41%, Other/unclear 53%). When comparing the patient questionnaire data with observed communication, we noticed that about a quarter of patients (24/105; 23%) expressed a different (complementary) motivation in the consultation with their clinician, then what they reported in the questionnaire. The remaining quarter (26/105; 25%) of patients thus expressed the same reason as reported in the questionnaire.

Regarding the care partners who accompanied the patient to the clinic, we also observed that more than half did not express their motivation for visiting the memory clinic (58/93; 62%, see Table 3). When combining data from patients and care partners, we found that for 43% of patients (45/105) neither the patient nor a care partner expressed during the consultation a motivation to seek care at the memory clinic. In addition, when both the patient and the care partner expressed a reason (25/93), different/complementing motivations were expressed in about half of these dyads (13/25).

Nineteen out of 105 (18%) of patients expressed an ‘other’ motivation, i.e., other than pre-defined in our coding scheme (see Box 1 and Table 3), which is a similar percentage as reported in the questionnaire. However, these are not all the same patients; only ten of these patients also reported an ‘other’ motivation in the questionnaire, indicating that patients can have multiple or multifaceted motivations. When taking a closer look at the ‘other’ motivations as expressed by the patients in the consultations, the central themes that were derived from the data were again wanting (i) **(more) information**, (ii) **access to care (services)**, and (iii) **treatment/advice**, as illustrated by the respective following quotes: “I want to know if I have a genetic predisposition (ID-1108)”, “It is intended that I will move to a nursing home (ID-5109)”, and “For my brain to work better again (ID-1105)”. Regarding the search for treatment/advice, some patients were rather specific in expressing their need for advice on how to deal with their symptoms or manage their disease, as illustrated by the following quotes: “[I want to know] if maybe, there are any possibilities to structure things more, or remember things better, or any aids or strategies to train myself maybe, or to change my eating habits (ID-3108)”, and “The only thing I think is, how do I go on? (ID-5117)”.

**Table 3**  
Motivations as expressed by patients and accompanying care partners in first consultation.

	Patients N = 105	Care partners N = 93
To confirm/exclude dementia	11 (11%)	10 (11%)
To find cause of symptoms	15 (15%)	19 (20%)
To confirm/exclude another diagnosis	5 (5%)	1 (1%)
Other	19 (18%)	5 (5%)
No motivation expressed	55 (52%)	58 (62%)

Note. Out of the 105 patients of which we successfully collected full audio-recordings of the first consultation, twelve were not accompanied by a care partner.

#### 4. Discussion and conclusion

In this multicenter study, we gathered empirical data on motivations that patients and their care partners have for visiting a memory clinic, using both self-reported questionnaire data and audio-recordings made of first memory clinic consultations. Next to finding a cause for their symptoms or complaints, patients may seek (more) information about their current diagnosis or the future, access to specific care service(s), and treatment or advice. Our findings indicate that most of the patients have rather specific and personal motivations for visiting a memory clinic, irrespective of syndrome diagnosis, and that complementary motivations often exist within patient-care partner dyads. Preferably, motivations of all patients and care partners should be addressed in memory clinic consultations, to enable personalized care.

Despite reporting clear motivations for visiting a memory clinic when prompted in a questionnaire, over half of patients did not express their motivation for seeking care during their first consultation in the memory clinic. The same goes for their accompanying care partners. In fact, in 43% of consultations, neither the patient nor the care partner expressed what they wanted to achieve at the memory clinic. Potential explanations could be that these patients and their care partners did not feel the need or assertive enough to voice their motivations, questions or needs, and/or that they simply had not yet thought that much about their motivations [17]. The quality of the interaction and the direction of the communication process could also have influenced the likelihood of patients and care partners expressing their motivations, as clinicians are most often in charge of the flow of information during (first) medical encounters, determining which topics and when they are discussed [11, 18,19]. Furthermore, the motivation that was reported by patients in the questionnaire, did not necessarily correspond to the motivation as voiced in the consultation. Since we asked them about their motivations in a questionnaire provided after the first consultation, the initial encounter with the clinician could have sparked additional questions or influenced their expectations of the diagnostic work-up. The observed discrepancy could also indicate that patients' motivations for seeking care and/or the goals that they want to achieve by visiting the clinic can be complex and multifaceted. Overall, our findings suggest that the diagnostic trajectory could start more often with a conversation about the motivations of patients and their accompanying care partners for visiting the memory clinic.

Of note, one-third of patients reported someone other than themselves as most concerned about their symptoms, often a partner or relative, and some patients explicitly reported that they only visited the memory clinic on someone else's request. These findings highlight the unique and important role of care partners in this clinical context [20, 21]. A triadic conversation about motivations and expectations would enable personalization of memory clinic care, considering both patients' and care partners' needs, by providing input for decisions that must be made about diagnostic testing and insight on which (detailed) information to provide [22]. Not attuning to their motivations for seeking care might result in unmet information needs, as frequently reported [11,18,23]. In addition, patients and care partners do not always get

what they are seeking, for example when it comes to curative treatment or certainty about the cause of symptoms [24], and this may lead to suboptimal satisfaction and (unnecessary) additional medical help seeking. The aforementioned conversation about an individual's motivation for seeking care may serve to manage the expectations of patients and their care partners regarding the diagnostic trajectory, potential results and implications of diagnostic testing, and treatment options, whilst at the same time optimally adjusting the diagnostic pathway and information provision to their needs.

Among the strengths of our study is that we gathered empirical data using both questionnaires and observational data collected in a variety of academic and local memory clinics at the start of the diagnostic trajectory, including a relatively large and heterogeneous group of patients and care partners. Our approach allowed for triangulation, by using different data collection methods, sources, and coders, thereby increasing the credibility and validity of our findings [25]. In addition, for the report of this study, we used consolidated reporting criteria (if relevant) [26]. Nevertheless, we cannot exclude the possibility of bias in our sample (e.g., by only including those who could read and write in Dutch) or in the data analysis process (e.g., since the coding process was led by two researchers with similar backgrounds). In addition, transferability of our results is potentially limited as we performed this multi-center study in the Netherlands, and motivations and information needs may differ by country. International replication is therefore warranted. In addition, self-reported motivation was enquired after with a single open-ended question in the questionnaire for patients, which was administered after the first consultation, possibly limiting or influencing the answers. Future research might include a more extensive questionnaire or interview prior to the first consultation, as this may provide more insight into the complexity of motivations, the differences between patients and their care partners, and barriers preventing them from discussing their motivations or expectations with their clinician.

##### 4.1. Practice implications

To stimulate conversations on motivations in clinical consultations, it is important to invite and support patients and care partners to express their motivations, needs, expectations and wishes regarding their visit to the memory clinic. A simple question by clinicians 'What do you hope or expect to achieve here, at the clinic?' could be a good starting point for such a conversation. However, triadic conversations about (potentially conflicting) expectations and needs can be difficult and require both patients and care partners to be actively involved [27]. Moreover, such conversations require specific skills from clinicians, who already have difficulty in assessing the (informational) needs and preferences of patients [28,29]. Evidenced-based communication skills training could support clinicians [30]. (E-)tools could be a way to support patients and care partners in their communication. A question prompt list, a structured list of example questions, is a simple, inexpensive and effective communication tool that can be used to facilitate patient and care partner participation in memory clinic consultations and to ensure patients' individual information needs are appropriately met [31]. In addition, educational videos are a good method of successfully informing individuals (with cognitive impairment) about what they can expect, and thereby preparing them for medical procedures and clinic visits [32]. Examples of animated videos and a QPL can be found on the ADappt platform (<https://www.ADappt.health>; see 'topic list') [33]. Although these tools still require (further) effectivity testing, these may be useful methods to support patients and their care partners in expressing their motivations, expectations, and needs and attune information provision accordingly.

##### 4.2. Conclusion

This qualitative study showed that most patients who visit the memory clinic want to find out what is causing their symptoms. In

addition, one in five patients has a primary motivation for visiting a memory clinic other than wanting to find a cause for their symptoms or confirming/excluding a (dementia) diagnosis. Although most patients are able to specify why they visit the memory clinic when prompted in a questionnaire, half of them does not discuss their motivation(s) for seeking care with their clinician. Often, neither the patient nor the care partner expresses what they want to achieve at the memory clinic. It is thus important to encourage clinicians, patients, and care partners to have a conversation on such motivations at the start of the diagnostic trajectory. This allows individualized information provision, better management of expectations, and effective tailoring of (diagnostic) care, and thus stimulates personalized medicine in memory clinics.

### CRedit authorship contribution statement

**LNCV:** Conceptualization, Investigation, Analysis, Writing – original draft. **AF:** Analysis, Writing – original draft. **MK:** Conceptualization, Investigation, Writing – review & editing. **FHB, NS, SSS, HAW, LH, MHdB, GR, LB, and MK:** Resources, Writing – review & editing. **EMAS:** Conceptualization, Supervision, Writing – review & editing. **WMvdf:** Conceptualization, Supervision, Writing – review & editing, Funding acquisition.

### Conflicts of interest

Research programs of Wiesje van der Flier (WvdF) have been funded by ZonMW, NWO, EU-FP7, EU-JPND, Alzheimer Nederland, Hersenstichting CardioVascular Onderzoek Nederland, Health~Holland, Topsector Life Sciences & Health, stichting Dioraphte, Gieskes-Strijbis fonds, stichting Equilibrio, Edwin Bouw fonds, Pasman stichting, stichting Alzheimer & Neuropsychiatrie Foundation, Philips, Biogen MA Inc, Novartis-NL, Life-MI, AVID, Roche BV, Fujifilm, and Combinostics. WF has performed contract research for Biogen MA Inc and Boehringer Ingelheim, and has been an invited speaker at Boehringer Ingelheim, Biogen MA Inc, Danone, Eisai, WebMD Neurology (Medscape), and Springer Healthcare. All funding is paid to her institution. Leonie Visser (LNCV) has been an invited speaker at Schwabe Group, fees were paid to her institution. All other authors declare no conflicts of interest.

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