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QUALITATIVE PAPER

Why to test for dementia: perspectives of patients, significant others and general practitioners

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Abstract

Background: This study aims to provide greater insight into the current decision-making process on diagnostic testing for dementia by exploring the expectations, needs and experiences of patients with memory complaints, significant others and general practitioners (GPs).
Methods: We performed semi-structured interviews with patients (>60 years) who consulted their GP on memory complaints, significant others and GPs. Participants were recruited until data saturation was reached in thematic analysis of interview transcripts.
Results: We performed 51 interviews (patients $n = 20$, significant others $n = 15$, GPs $n = 16$). Thematic analysis revealed four themes: (i) 'drivers to (not) testing', i.e. need to act on symptoms, beliefs on the necessity and expected outcomes of diagnostic testing; (ii) 'patient preferences and context are critical in the actual decision', i.e. in the actual decision-making process interpretation of symptoms, GPs' desire to meet patient preferences, social context and healthcare system dynamics guided the decision; (iii) 'need for individualised communication in the decision-making process', i.e. for patients feeling heard was a prerequisite for decision-making and GPs tailored communication strategies to individual patients and (iv) 'GP practice and barriers to shared decision-making (SDM)', i.e. although GPs value SDM in the decision on diagnostic testing for dementia, patients express limited awareness of the decision and options at stake.
Conclusions: Decision-making on diagnostic testing for dementia is a multifactorial and preference-guided process for all involved stakeholders, but decisions are often not explicitly jointly made. Development of patient decision aids could facilitate better involvement and more informed choices by patients.

Keywords: dementia, general practice, diagnostic testing, patient preferences, qualitative research, older people

Key Points

- Patients with memory complaints show diversity in drivers underlying their preferences for diagnostic testing for dementia.
- The actual decision-making process on diagnostic testing for dementia is guided by patients' preferences and context.
- Although shared decision-making (SDM) is valued by GPs, decisions on diagnostic testing are often not explicitly jointly made.

- Patients express limited awareness of the decision and options at stake.
- Clarifying and strengthening decisional roles will facilitate SDM on diagnostic testing for dementia in practice.

Introduction

As people live longer, dementia is becoming a more prominent issue for society. In the Netherlands, more than half a million people will live with dementia by 2040 [1]. Most people with dementia are diagnosed when their daily living is significantly impacted by cognitive decline [2]. However, opportunities for earlier biomarker-based diagnoses are growing and are finding their way into clinical practice [3, 4]. Although aiming for earlier diagnoses can be beneficial due to opportunities for information on prognosis, arranging care and supporting informal caregivers [5–7], diagnosing early also has drawbacks such as depression, anxiety, experiencing stigma and uncertainties about the prognosis in an early stage [8–10]. Moreover, early diagnosis is not necessarily associated with improvements in quality of life for people with memory complaints and their significant others [11]. Clinicians question the value of these biomarkers in clinical practice in light of a lack of curative treatment for dementia. Instead, they stress the importance of meeting a person's wishes in the timing of a dementia diagnosis [12, 13]. The desirable timing for a dementia diagnosis depends on the individual context and needs of the patient and his/her significant other [14, 15], making it a preference-based decision.

General practitioners (GPs) are usually the first healthcare professional contacted when people become worried about their memory. Together with the person with memory complaints and (most of the time) their significant other, GPs decide upon the initiation of diagnostic testing for dementia. Although patients' options may depend on their medical history and context, most patients have three options in deciding on starting a diagnostic process for dementia: (i) to wait and see ('watchful waiting'), (ii) diagnostic testing in primary care and (iii) referral for specialised diagnostic testing to a memory clinic or geriatrician. In the Netherlands, GPs are encouraged to make dementia diagnoses in primary care. Also, GPs act as gatekeepers for access to specialised diagnostic testing [16]. The practice guideline of the Dutch College of General Practitioners on 'Dementia' recommends shared decision-making (SDM) when considering starting a diagnostic trajectory and stresses the importance of the patient's autonomy in this decision [16]. SDM has been defined as 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences' [p1361, 17]. When patients make decisions based on informed preferences, decisions are based on more accurate expectations about the negative and positive consequences and are more consistent with personal preferences [18]. To realise these informed preferences, identification of a patient's goals and values of care is key, especially in older adults [19]. Considering diagnostic testing for dementia often involves significant others, who may have different or conflicting goals or values than the person with memory complaints [20], which can complicate the SDM process.

Although general practice is suggested to be the setting where preferences for diagnostic testing are formed and SDM should be initiated [16, 21], little is known about which factors drive the decision-making process on initiating diagnostic testing in general practice and how it is experienced by the persons involved. We, therefore, aimed to answer the following research question: What are the key factors forming preferences for diagnostic testing for dementia, and how do patients with memory complaints, their significant others and GPs experience the (shared) decision-making process? These results could contribute to improved SDM on starting dementia diagnostics in general practice.

Methods

Study design

A qualitative interview study with a reflexive approach to thematic analysis guided by the theoretical framework of Braun and Clarke [22, 23] was performed. The COREQ criteria (COnsolidated criteria for REporting Qualitative research) were followed in reporting the results [24] (Appendix 1). Data collection was part of the S-DeciDeD project [25] and was approved by the Medical Review Ethics Committee of the Maastricht University Medical Center (MUMC+) (number 2018–0333). Contributing researchers are trained and experienced in qualitative research methodology, primary care research, clinical neuropsychology and patient involvement in health decision-making. Several researchers also have clinical backgrounds: CW and RP are experienced neuropsychologists in memory clinics; MP is a general practitioner with dementia expertise.

Setting and participants

We included the key stakeholders in the decision-making process on starting diagnostic testing for dementia in Dutch general practices: patients with memory complaints, significant others and GPs. All participants were recruited using purposive sampling. We aimed for variation in patient characteristics (e.g. age and decision on starting a diagnostic trajectory for dementia—i.e. to wait and see, diagnostic testing in general practice or referral for specialised diagnostic testing) and professional characteristics (e.g. age, experience with dementia, and size and location of the general practice). Patients were eligible for inclusion if they were aged 60 years

Table 1. Inclusion and exclusion criteria for patients.

Inclusion	Exclusion
• Aged 60 years or older	• A severe mental illness in the last 12 months such as schizophrenia, depression or bipolar disorder
• Had a consultation with GP on memory complaints in which a decision on starting diagnostic trajectory is made (i.e. wait and see, diagnostic testing in primary care, referral for specialised diagnostic testing) maximum 3 months before inclusion	• A life-threatening comorbid illness
• Being able to participate in a telephone interview and decisional capacity to provide informed consent	

or older and visited their GP because of memory complaints (Table 1). The age limit was chosen to exclude patients with young-onset dementia as the dynamics of these prediagnostic trajectories are usually different than in older patients [26].

Participating significant others could be spouses, children (in law), other close relatives or friends and mentioned by the patient as someone closely involved in the decision-making process. There were no inclusion or exclusion criteria for GPs. Participants were recruited via general practices located in the south-eastern part of the Netherlands participating in the S-DeciDeD project and via the memory clinic of the MUMC+ in Maastricht between January 2020 and December 2021. GPs were asked via telephone or email if they were interested to participate in a telephone interview. In case GPs indicated that mainly their practice nurses were involved in decision-making on diagnostic testing for dementia, the practice nurse was invited to participate. Furthermore, referring GPs of patients who were recruited via the memory clinic were invited to participate. All participants provided written informed consent and were given a gift card after participation.

Data collection

Semi-structured interviews were performed between March 2020 and December 2021. All interviews were conducted by telephone, lasted between 20 and 45 min, and were conducted by a researcher (IL, psychologist, PhD student, female) or one trained research assistant (psychologist). Patients and significant others were interviewed individually. In two interviews with patients, a significant other was present because the patient felt insecure doing the interview by him/herself because of their cognitive impairment. In all other interviews, no one other than the participant was present. All participants were informed of the research goals through the informed consent form. All participants had no prior relationship with the interviewers. In case patients had been referred to a memory clinic, interviews were conducted before they visited the memory clinic, and thus before diagnostic testing, to ensure their reflections and experiences were not influenced by the course or outcome of diagnostic testing. Interviews were guided by topic lists (Appendix 2). Topics included experiences with the decision-making process, attitudes towards (early) diagnostic testing and experienced role in the decision-making process. Topic lists for each stakeholder were tested once in a telephone-based semi-structured interview with the corresponding stakeholder, after which the formulations of the questions were slightly modified. Upon inclusion, patients were asked to permit the researchers to obtain medical records of their consultations on memory complaints. The decision on diagnostic testing, number of consultations on memory complaints and (if available) diagnostic screening test scores were extracted from the patient's medical record. Topic lists for patients and significant others were individualised based on the decision on diagnostic testing present in the patient's medical records. Field notes were made after each interview. Interviews were audio-taped and transcribed verbatim. Transcripts were not returned for member checks. Data saturation together for patients and significant others, and separately for GPs was discussed in frequent meetings within the research team. Enrolment of participants ended when data saturation was reached for answering the main research questions and no new concepts emerged [27], which was confirmed with one additional interview per stakeholder group. Repeat interviews were not performed.

Data analysis

The guiding theoretical framework for data analysis was a reflexive approach to thematic analysis as per Braun and Clarke [22, 23]. This approach enabled us to gain an understanding of the subjective experiences of participants while also reflecting on the influence of our own interpretations as researchers. Furthermore, analysis was informed by findings of our earlier integrative review on preferences for starting diagnostic testing for dementia [15]. We started coding inductively to minimise bias and when starting to fit our codes/code groups into the review's framework, we explicitly questioned ourselves and discussed with the team whether codes were congruent with the framework or whether they represented something new. In these discussion meetings, we attempted to balance the different clinical and research perspectives.

Data analysis was an iterative process consisting of five phases supported by ATLAS.ti (version 22). This process and a description of the review's framework are illustrated in Appendix 3. First, after familiarising with the data, all transcripts were inductively coded. Second, we used a deductive coding structure guided by the review's framework [15]. Third, codes were structured into code groups from the review's framework or in new (inductive) code groups. In order to do so, both inductive and deductive codes were compared and similar codes were grouped into code groups. Patient and significant others' interviews were coded independently by two coders (IL and CT (research intern, female)); afterwards, these codes were compared and grouped into code groups by IL and CW (senior researcher, clinical neuropsychologist, female). GP interviews were coded, compared and grouped into code groups by IL and MH (psychologist, PhD student, female). Fourth, inductive and deductive code groups were aggregated. In the final phase, code groups of all stakeholders were compared, triangulated and categorised to create themes. During this phase, code groups were rephrased, and new code groups were formulated. During this iterative process, regular discussion in research meetings (IL, CW and MP (senior researcher, GP, female)) took place in which codes (groups) were rephrased, added or redefined, previously coded data were compared and codes or code groups were if necessary adapted based on the data. Participants did not provide feedback on the findings, to avoid patients' and significant others' considerations to be influenced by the outcome or course of their diagnostic trajectory.

Results

Study population

Between January 2020 and December 2021, we approached 39 primary care healthcare professionals and 55 patients with memory complaints and their significant others. Ultimately, we conducted 51 interviews: 16 with primary care healthcare professionals (14 GPs and 2 practice nurses) (in the remainder of this paper denoted as 'GPs'), 20 with people with memory complaints and 15 with significant others of people with memory complaints (see Figure 1). Table 2 summarises the population characteristics and shows that the sampling strategy resulted in variation in most characteristics. We were not able to include patients who pursued a wait-and-see strategy. Not all included patients had a significant other who was willing to participate in the study. Available diagnostic screening test scores (i.e. Mini-Mental State Examination Test (max. score = 30), $n = 16$, $n = 3$ missing, $n = 1$ invalid due to delirium) of patients ranged between 19 and 30, with a mean of 25.9 ($SD = 2.9$). Two patients had an MMSE score lower than 24 indicative of moderate cognitive impairment [16].

Four themes were identified. Table 3 shows these themes and the corresponding codes. The themes are described below and illustrated by participant quotations (Table 4). In each theme, the perspective of every stakeholder is described, resulting from triangulation of patients', significant others' and GPs' perspectives. In theme 1, stakeholders held different perspectives, whereas in themes 2–4, stakeholders' views were more aligned.

Theme 1: drivers to (not) testing

Patients, significant others and GPs mentioned a variety of underlying attitudes, values and expected outcomes contributing to their preference regarding starting dementia diagnostics.

The feeling of needing to do something

Patients and significant others had this feeling of 'needing to do something', which was often described as 'the ability to take matters into your own hands', 'acting for your own good' and 'knowing I did everything I could'. These feelings were more pronounced in patients referred to a memory clinic.

Beliefs on the necessity of diagnostic testing

Diagnostic testing was often believed necessary to provide or receive good quality healthcare by patients, significant others as well as GPs. Moreover, patients and significant others believed diagnostic testing was needed to fulfil their perceived need or right to know the cause of the symptoms. Some patients believed this need could be fulfilled by dementia diagnostics in primary care whereas others believed specialised diagnostic testing was needed to fulfil this need.

Patients who were not referred to secondary care often believed their memory complaints were a fact of life that coincides with ageing, which were not worth the efforts of further investigation. Some of these patients did not pursue specialised diagnostic testing because this would worry their children and they did not perceive their complaints to be severe enough for them to worry about.

Especially GPs, but also some significant others believed the lack of effective treatment was a reason to not pursue (early) specialised diagnostic testing.

Expected outcomes of diagnostic testing

Although patients, significant others as well as GPs viewed a possible diagnosis as bad news, they had expectations of opportunities or tools to improve the patient's quality of life as an outcome of diagnostic testing, which overshadowed the possible negative prospect a diagnosis would bring. These could be expectations of (medicinal) treatment, prevention strategies, support, or practical tips and tricks to handle the complaints or behaviour of the person with memory complaints, which were motives to pursue diagnostic testing. Expectations of tools to improve the patient's quality of life were more pronounced in referred patients.

Patients and significant others as well as GPs expected or hoped that diagnostic testing would clarify the cause of the symptoms, which was in itself considered a positive outcome.

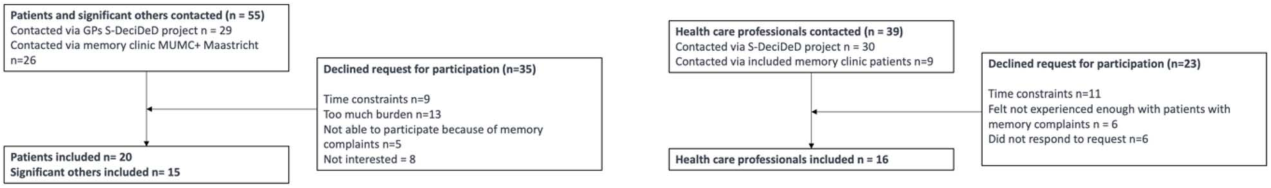

Figure 1. Flowchart patient, significant other and healthcare professional inclusion.

Table 2. Population characteristics (*N* = 51).

General practitioner (*n* = 14)	
Age, years, mean (min–max)	49 (32–65)
Sex, female, *n*	9
Years of experience as GP, mean (min–max)	15 (3–30)
Specific postgraduate education in dementia/ageing, *n*	2
Practice location	
Rural	0
Urban	14
Type of practice	
Small (1–2 GPs)	10
Large (3 or more GPs)	4
Practice nurse (*n* = 2)	
Age, years, mean (min–max)	63 (59–68)
Sex, female, *n*	2
Years of experience as a practice-based nurse, mean (min–max)	12 (9–15)
Specific postgraduate education in dementia/ageing, *n*	0
Practice location	
Rural	0
Urban	2
Type of practice	
Small (1–2 GPs)	0
Large (3 or more GPs)	2
Patients with memory complaints (*n* = 20)	
Age, years, mean (min–max)	72 (63–82)
Sex, female, *n*	8
Education level*	
Low	7
Middle	7
High	6
Living situation	
Alone	5
With partner	15
Decision on diagnostic testing memory complaints	
To wait and see	0
Diagnostic testing in general practice	6
Referral to a specialist	14
Number of consultations on memory complaints, mean (min–max)	3 (1–7)
Significant other (*n* = 15)	
Age, years, mean (min–max)	69 (50–82)
Sex, female, *n*	12
Education level*	
Low	6
Middle	4
High	5
Type of relationship with the patient with memory complaints	
Spouse	12
Child	3

Note. *Educational level was categorised into low (at most primary education), mid (junior vocational education) and high (senior vocational or academic education) according to a Dutch grading system [28], which is comparable with the Standard Classification of Education [29].

This need for clarity was present in both referred patients and significant others and those who stayed in the primary care setting.

GPs, however, were also cautious in starting diagnostic testing because they were aware that a diagnosis could also lead to a decrease in quality of life for some patients through

Table 3. Themes, categories and codes.

Themes	Categories	Codes
1. Drivers to (not) testing	**1.1. Feeling of needing to do something (PT, SO)**	Ability to take matters into your own hands Acting for your own good Knowing I did everything I could Strengthened by family history/experience with dementia
	1.2. Beliefs on the necessity of diagnostic testing (GP, PT, SO)	Needed for providing good quality care Improves or maintains quality of life Treatment not possible Patients' need to know Memory complaints are part of ageing
	1.3. Expected outcomes of diagnostic testing (GP, PT, SO)	Clarity on cause symptoms or reassurance Opportunities or tools to improve quality of life Decrease in quality of life patient
	1.4. GPs' preferences are guided by patient characteristics (GP)	Age Education level Mobility
2. Patient preferences and context are critical in the actual decision	2.1. Symptom interpretation guides perceived diagnostic necessity (GP, PT, SO)	Interpretation of symptoms by patient and significant other **Normalisation or validation of symptoms** **Health status of the patient** Outcome diagnostic testing general practice
	2.2. Meeting patients' and significant others' needs and preferences (GP)	Fear to develop dementia Care request Attitude towards diagnostic testing Request for referral or to stay in general practice
	2.3. Social context and healthcare system dynamics (GP, PT, SO)	Healthcare system mechanisms **Support of friends and family** **Presence or lack of social network**
3. Need for individualised communication in the decision-making process	3.1. Feeling heard as a key prerequisite for decision-making (PT, SO)	Feeling comfortable to talk about symptoms with GP Feeling heard by GP Feeling not taken seriously Goal diagnostic testing not explained
	3.2. Tailoring communication strategies: balancing patient autonomy and expectations (GP)	Letting patient know he/she stays in charge Managing expectations regarding (specialised) diagnostic testing Gentle approach dependent on behaviour patient
4. Shared decision-making is valued but scarcely practised	4.1. Patients' limited awareness of the decision and options at stake (PT, SO)	Perceived role in decision-making process Perceived SDM by patient and significant others Experienced decisional conflict dependent on need to know Experienced decisional conflict dependent on expected reassurance Difficult choice because of fear for dementia Trust it will fall into place Trust information provided is enough Further information needed; What does specialised diagnostic testing entail? Further information needed; What is the difference between cognitive decline due to ageing and due to dementia?
	4.2. GP practice and barriers to shared decision-making (GP)	Barriers and facilitators Patient need for SDM SDM in practice

Note. GP = general practitioner, PT = patient, SO = significant other. Categories and codes in bold can be directly traced back to the deductive coding structure [15].

psychological distress or a decrease in patient autonomy (e.g. driving status, being stigmatised).

GPs' preferences are guided by patient characteristics

GPs did not have a dominant preference towards if, when and how diagnostic testing for dementia should be initiated. Their preference was influenced by patient characteristics such as age, education level, patients' mobility and comorbidity. Participant quotations to support theme 1 can be found in Table 4.

Theme 2: patient preferences and context are critical in the actual decision

Symptom interpretation guides perceived diagnostic necessity

For GPs, both their own perception of the severity of the patient's symptoms, and the interpretation of symptoms by the patient and the significant other, influenced their perceived necessity of diagnostic testing. When patients, but especially significant others, experienced the impact of memory complaints on their daily living as troublesome, GPs were more inclined to start diagnostic testing. For

Table 4. Derived themes with illustrative participant quotations.

Theme	Category	Participant	Quote
1. Drivers to (not) testing	**1.1. Feelings of needing to do something (PT, SO)**	Patient (female, age 66, referred)	‘At least I know that I have done what I could do while I still can’
		Significant other (male, age 80, referred)	‘Simply being aware of the situation enables you to take action’
	1.2. Beliefs on the necessity of diagnostic testing (GP, PT, SO)	Significant other (age 49, referred)	‘And I also found that a pleasant thing, look in general practice, the GP conducts the test by himself. While I think here [the memory clinic] it really goes much deeper into the problem itself’
		Patient (age 76, general practice)	‘I do not want to make a big fuss about it (i.e. specialised diagnostic testing) now that it is not yet necessary. I do not want to burden the children’
		GP (female, age 40)	‘As a GP, you naturally worry about giving people more years of illness, without it having any consequence for treatment. That would be a shame’
	1.3. Expected outcomes of diagnostic testing (GP, PT, SO)	Patient (age 66, male, referred)	‘Well, the most important thing about having diagnostic testing done at the memory clinic is whether there are possible treatments, not necessarily medication, but tools such as training and the like to prevent complaints from getting worse’
		Significant other (male, age 48, referred)	I hope to have some clarity after the appointment [at the memory clinic]. Is it indeed related to elderly dementia or Alzheimer’s-like conditions? Or could there be something not quite right in the head?
		GP (female, age 55)	‘The most important thing is that they do not become depressed. I think you have to be a little vigilant about that’
	1.4. GPs’ preferences are guided by patient characteristics	Practice nurse (female, age 67)	‘With elderly people, let’s say above eighty years old with moderate memory complaints, it is questionable what the added value of a memory clinic is. In our practice, we often prefer to do the diagnostic testing ourselves then’
2. Patient preferences and context are critical in the actual decision	2.1. Symptom interpretation guides perceived diagnostic necessity (GP, PT, SO)	GP (male, age 65)	‘It obviously depends on to what extent people experience symptoms, whether it is something they worry about or whether it is something they report as a fact of life inherently to ageing’
		Patient (male, age 66, referred)	‘Look, if my mother had not had dementia, I would not even have considered going to the memory clinic. Then I would not have any reason to act at all’
		Patient (male, age 82, general practice)	‘My kids keep saying dad get over yourself it is not so bad. But I think it’s getting worse’
	2.2. Meeting patients’ and significant others’ needs and preferences (GP)	GP (male, age 32)	‘If someone has it all figured out and says “I want to go to the memory clinic.” And I say “this are still the options, think about it” and that patient thinks about it for a week and stays with it then of course I’m not the one stopping that’
	2.3. Social context and healthcare system dynamics (GP, PT, SO)	Patient (female, age 68, referred)	‘My son encourages me in all the options. If I think it is a good idea, he has my back’
		GP (male, age 39)	‘Look when I refer, it is very often that I find my own options in primary care too limited to be able to help someone properly’
3. Need for individualised communication in the decision-making process	3.1. Feeling heard as a key prerequisite for decision-making (PT, SO)	Significant other (female, age 73, referred)	‘We could get along well and we just felt that he was serious about it. He administered the tests seriously and afterwards he did very well in that conversation—very clear. He also gave the feeling that there is indeed something going on, and we will investigate further. That also gives you peace of mind’
		Patient (female, age 65, referred)	‘It was nice to have a listening ear’
	3.2. Tailoring communication strategies: balancing patient autonomy and expectations (GP)	GP (female, age 34)	‘Usually I tell them “It is not that we will decide everything for you, you always remain in charge”’
		GP (female, age 55)	‘Many people still often believe that there is a pill or some intervention to slow down dementia. While we do have cholinesterase inhibitors, their effectiveness is quite limited, to say the least. I believe expectation management in this regard is crucial

(continued)

Table 4. Continued.

Theme	Category	Participant	Quote
4. Shared decision-making is valued but scarcely practised	4.1. Patients' limited awareness of the decision and options at stake (PT, SO)	Patient (male, age 81, referred)	'I would not know what kind of choice to make, I can hardly say to a doctor: you should do that and that'
		Patient (female, age 76, referred)	[Interviewer]: Did the GP discuss options on diagnostic testing with you? 'No he just told me that it would be a good idea to go to the memory clinic'
		Significant other (female, age 73, referred)	[Interviewer]: And did you find it a difficult choice to be referred? 'No no. It just makes it all clear, you want to know what's going on so it's fine for it to continue'
		Patient (male, age 73, referred)	'I trusted the information provided by the practice nurse was everything I needed to know'
	4.2. GP practice and barriers to shared decision-making (GP)	Practice nurse (female, age 59)	'Patients like to have a voice in deciding on their health'
		GP (female, age 43)	'I definitely apply SDM. I think you must get someone motivated to undergo further diagnostic testing. If I refer someone who doesn't want to, they're not going to cooperate with that either, are they?'

Note. GP = general practitioner, PT = patient, SO = significant other. Categories and codes in bold can be directly traced back to the deductive coding structure [15].

patients and significant others, the normalisation or validation of memory complaints by their social environment was crucial in guiding the actual decision. When symptoms were normalised, patients were less inclined to pursue specialised diagnostic testing, whereas if the severity of the symptoms was confirmed by family members or friends (e.g. social contacts outside of their home), patients and significant others perceived a necessity to pursue (specialised) diagnostic testing, and their 'need to know' was emphasised.

A family history of dementia was also important in the way the severity of symptoms was interpreted by patients and significant others. Feelings of needing to do something or beliefs on the necessity of diagnostic testing were strengthened thereby.

In the decision to refer, the outcome of diagnostic testing in primary care was perceived as a base to interpret the severity of symptoms and therewith determine the necessity of specialised diagnostic testing for patients, significant others as well as GPs. In case GPs were uncertain about referral after diagnostic testing in primary care, they consulted the patient and his/her significant other on their preferences but were more inclined to refer.

Meeting patients' and significant others' needs and preferences

In the actual decision-making process, GPs were mainly guided by patients' needs and preferences. Especially, the decision on early specialised diagnostic testing for dementia was perceived as highly preference sensitive. When patients or significant others appeared to be fearful of developing dementia or preferred specialised diagnostic testing, GPs were more inclined to refer them. Furthermore, meeting patients' care needs was important in determining the necessity of diagnostic testing for GPs. To meet specific care needs such as arranging home care, GPs could perceive diagnostic testing as necessary. On the other hand, when patients were hesitant to discuss their complaints and did not have care needs, GPs indicated pursuing a wait-and-see strategy.

Social context and healthcare system dynamics

The social context of the patient could influence the decision to start diagnostic testing. When patients felt supported by close relatives or friends to pursue specialised diagnostic testing, they were more inclined to do so.

At the same time, for GPs the presence of a social support system for the patient was important in deciding upon diagnostic testing. They were often needed to take history, determine care needs or discuss the possibility of referral.

The healthcare system could also provide context that guided the decision to refer for GPs. Some GPs indicated they needed a dementia diagnosis confirmed by a specialist to arrange care, whereas others mentioned that social prescribing did not require a precise diagnosis. GPs' workload or lack of confidence in their diagnostic skills made them more inclined to refer. Participant quotations to support theme 2 can be found in Table 4.

Theme 3: need for individualised communication in the decision-making process

Feeling heard as key prerequisite for decision-making

For many patients and significant others, the most important thing in the decision-making process on diagnostic testing was to be taken seriously in their worries about memory complaints. Although most patients described that they felt being taken seriously and felt comfortable talking about their symptoms with their GP, some significant others felt their concerns were not taken seriously by their GP.

Tailoring communication strategies: balancing patient autonomy and expectations

GPs valued patients' autonomy in the decision-making process and tried to communicate to the patient that he/she is in charge during the process. This, however, could be difficult if patients were hesitant to discuss their complaints or had limited self-awareness of their cognitive problems. GPs described often taking a gentle approach in communicating about dementia diagnostics with these patients. This could result in withholding the true goal of diagnostic testing from patients. The word 'dementia' was then avoided, and diagnostic testing was placed in a broader context of healthcare screening for older patients. At the same time, in patients or significant others with unrealistic expectations of referral or treatment, GPs tried to shape realistic expectations of specialised diagnostic testing to guide patients to an informed decision. Participant quotations to support theme 3 can be found in Table 4.

Theme 4: shared decision-making is valued but scarcely practised

Patients' limited awareness of the decision and options at stake

Perceptions of their role in the decision-making process varied between patients. Some patients expressed not being aware they had an active role in the decision-making process or that a choice was to be made, whereas others perceived it as a mutual decision together with their significant other and their GP. Some patients mentioned their significant other had a more active role in the decision on referral for specialised diagnostic testing. In these cases, significant others asked for specialised diagnostic testing, whereas these patients themselves did not perceive referral as necessary. Often patients agreed to undergo specialised diagnostic testing to meet the preferences of their significant other.

None of the patients and significant others could recall their GP explaining options (i.e. to wait and see, diagnostic testing in primary care or referral for specialised diagnostic testing) or discussing what was important to them as a patient during the decision-making process. Most patients and significant others mentioned though to be satisfied with their role in the decision-making process.

In the decision-making process, most patients and significant others were driven by a pressing need to know, the desire to act or the expectation of reassurance from diagnostic testing. Consequently, most patients felt limited need to seek or receive comprehensive information about the possible consequences of diagnostic testing for dementia. They trusted their GPs' expertise and decisions or were not aware of the options available to them. However, patients who feared a dementia diagnosis experienced more uncertainty in their decision-making. These patients wondered if they were provided with enough information on dementia diagnostics by their GP. They had questions about what specialised diagnostic testing entailed or still wondered if they should be worried about their cognitive decline.

GP practice and barriers to shared decision-making

Most GPs valued SDM and patient involvement in the decision to start diagnostic testing and thought their patients would equally value SDM. The decision-making process is often described as a gradual process by GPs. The way GPs applied SDM to reach a decision, however, varied. Some GPs suggest being explicit with patients and their significant others about the need to make a choice in which their participation is valuable, while others described a more subtle approach or not mentioning it at all. Few GPs indicated presenting options for diagnostic testing to patients and discussing the advantages and disadvantages of each option. At the same time, others indicated steering patients in a certain direction if they thought that was the best option or viewed SDM as a tool to motivate patients to undergo further diagnostic testing.

Although GPs valued SDM, they had difficulties in involving patients with severe memory complaints, limited awareness of their (memory) problems or a limited social support system in the decision-making process. A good social support system or pre-existing knowledge of dementia or memory complaints facilitated SDM according to GPs. Participant quotations to support theme 1 can be found in Table 4.

Discussion

This qualitative study explored the decision-making process on dementia diagnostics in general practice with key stakeholders. It showed that each stakeholder (i.e. the patient with memory complaints, significant other and GPs) enters the decision-making process with his/her own preference. The drivers underlying these preferences can vary widely between and within stakeholder groups and can in turn be influenced or constructed during the clinical encounter in general practice. Most patients and significant others are guided by their hope or need for either clarity on their symptoms or support or tools to improve their quality of life. GPs' preferences are similar but are also guided by patient characteristics such as age and comorbidity. The decision-making process could to a varying degree be shaped by the perceived severity of the patient's symptoms, contextual factors, and the extent to which the GP meets the patients' needs and preferences. In practice, decisions are often not explicitly shared; patients do not perceive they have options to choose from and GPs feel cognitive symptoms limit involvement.

Earlier studies showed GPs had mixed attitudes towards dementia diagnostics in light of diagnostic or therapeutic nihilism [30, 31]. GPs in our study also tended to be careful in referring patients for specialised diagnostic testing in an early stage because of the lack of effective medicinal treatment. Accordingly, they tried to manage patients' expectations of referral with regard to therapeutic options, supported by the Dutch general practice guideline [16] on dementia that currently discourages medicinal treatment due to side effects and minimal improvement in patients' quality of life. This may reduce the significance of medicinal treatment as an important factor for referral compared to previous studies [30, 31].

Our study shows that GPs value SDM in the decision-making process on diagnostic testing for dementia and they indicate applying SDM in most decision-making processes with patients. Patients and significant others, however, often did not experience or take an active role in the decision-making process. Although they generally felt heard and taken seriously, the decision on diagnostic testing was often attributed to the GP. This discrepancy could be explained by patients' assumptions that there is no decision to be made for which their involvement is required. Earlier literature suggests that patients may perceive this because they believe they are not entitled to participate in the decision-making process, believe 'doctor knows best' or desire to be a 'good' (i.e. passive) patient [32]. At the same time, clinicians may (unconsciously) present the options in a biased way [33, 34], as GPs in our study tried to guide to decision in a direction they felt was best for the patient. Moreover, physicians are known to not actually actively invite patients to participate in decision-making in contrast to their own belief that they do [33, 34]. Moreover, our study suggests that GPs tend to avoid clear communication on diagnostic testing for dementia in patients with limited awareness in their cognitive problems, which hinders patient involvement in decision-making. One way to facilitate patient involvement is by using patient decision aids which can be helpful in clarifying and strengthening the decisional roles of GPs as well as patients and significant others [25].

Related to this, patients included in this study visited their GP because of memory complaints; GPs may thus have involved patients in the decision-making process, but patients do not remember this or did not experience they had a problem for which decision-making was required because of limited awareness of their memory complaints. However, most significant others included in the study did not experience an active role in the decision-making process either. Earlier research suggested that people in general have difficulties in recalling information from consultations with healthcare professionals and often do not recall a choice had to be made for which their involvement was required [34, 35].

Our findings suggest that the perceived decisional conflict in most patients and significant others in the decision on diagnostic testing is low and information needs on diagnostic testing for dementia are limited. This finding seems to be in contrast with the perception that deciding on diagnostic testing for dementia is difficult for patients with memory complaints and their significant others [2, 36]. However, older patients may not perceive a need to choose between options because they generally have a greater tendency to defer decisions to healthcare professionals compared to younger patients, which in the case of deciding diagnostic testing on dementia could be amplified due the complex nature of the decision [33]. Moreover, our findings suggest that GPs often embark on diagnostic testing without necessarily presenting pros and cons of doing so. This results in little understanding by patients and SO that there is a choice to make, consequently less patient involvement in decision-making. Furthermore, most patients in our study attributed their low level of decisional conflict to their pressing need to know, their urge to do something about the symptoms or had a positive outcome expectation. When those needs and values were in accordance with the GPs' preferred course of action, the patients' and significant others' needs were aligned with the choice made, resulting in lower decisional conflict and limited information needs [37]. These needs and values were possibly more present in our sample, as we were only able to include patients who underwent diagnostic testing.

This study has several strengths and limitations worth discussing. First, we ensured that all possible perspectives were captured in our data by including the key stakeholders involved in the decision-making process. Moreover, we tried to include patients in each decision category (i.e. to wait and see, diagnostics in primary care and referral to a memory clinic). Second, our data were analysed independently by two coders and frequently discussed in research meetings thereby increasing reflexivity of researchers' characteristics or presumptions. The researchers involved have different backgrounds, occupations and (clinical) experiences, which contributed to investigator triangulation. However, we were only able to include patients in whom the decision to start diagnostic testing was already made (either in primary care or through referral). During recruitment, GPs appeared hesitant to ask patients who had pursued a wait-and-see strategy for diagnostic testing to participate in the study. Older patients were also more hesitant and restricted from scheduling appointments with their GP due to the COVID-19 pandemic [38], which may have resulted in GPs encountering more patients with more sense of urgency to do something. Moreover, patients included in our study seemed to have relatively mild memory complaints. Preferences for diagnostic testing and experiences during the decision-making process might be different for patients and significant others in light of severe memory complaints. Both aspects limit the generalisability of our findings. Lastly, all interviews were conducted by telephone due to difficulties in scheduling with GPs and the COVID-19 pandemic. However, previous research showed that there is no evidence of reduced quality of findings, data loss or distortion due to telephone interviews compared to face-to-face interviews [39, 40].

In conclusion, this study shows that patients and significant others have a large variety of drivers underlying their preferences for initiating diagnostic testing for dementia, which underlines the importance of SDM in this area. GPs' preferences are grounded on their aim to achieve the best quality life for their patients, which has common ground with patients' preferences. Although GPs' emphasis is on providing person-centred care, patients and significant others often do not experience having a choice and consequently involvement in SDM, which emphasises the need for more explicit patient involvement. Development of patient decision aids could facilitate better involvement and more informed choices by patients.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Appendix 1. COREQ checklist

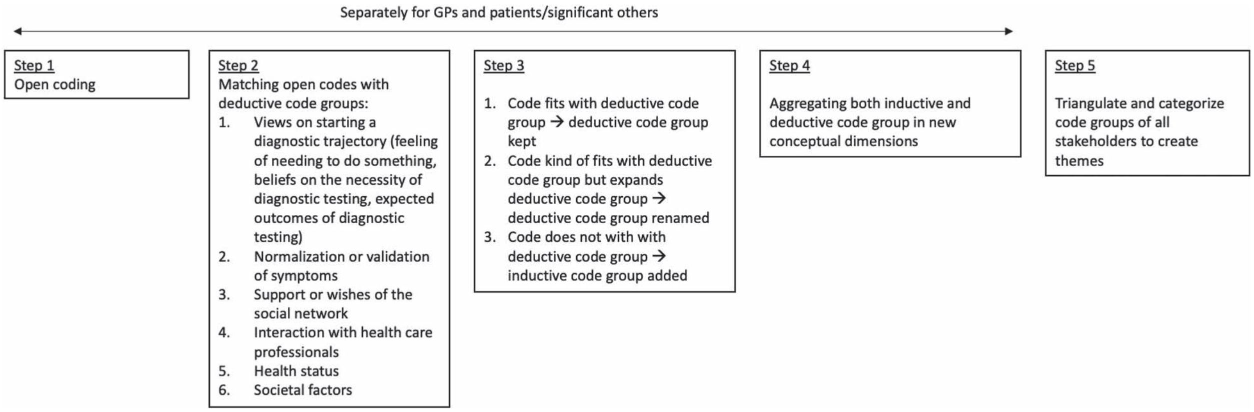
No. Item	Guide questions/description	Reported on page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	5
2. Credentials	What were the researcher's credentials? e.g. PhD, MD	4–6
3. Occupation	What was their occupation at the time of the study?	4–6
4. Gender	Was the researcher male or female?	4–6
5. Experience and training	What experience or training did the researcher have?	4–6
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	6
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. Grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection		
10. Sampling	How were participants selected? e.g. Purposive, convenience, consecutive, snowball	4
11. Method of approach	How were participants approached? e.g. Face-to-face, telephone, mail, email	5–6
12. Sample size	How many participants were in the study?	7
13. Non-participation	How many people refused to participate or dropped out? Reasons?	7
Setting		
14. Setting of data collection	Where was the data collected? e.g. Home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	5
16. Description of sample	What are the important characteristics of the sample? e.g. Demographic data, date	8
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6, Appendix 2
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	6
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	6
20. Field notes	Were field notes made during and/or after the interview or focus group?	6
21. Duration	What was the duration of the interviews or focus group?	5
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	7
25. Description of the coding tree	Did authors provide a description of the coding tree?	14, 15 (Table 3)
26. Derivation of themes	Were themes identified in advance or derived from the data?	6, 7
27. Software	What software, if applicable, was used to manage the data?	6
28. Participant checking	Did participants provide feedback on the findings?	6
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. Participant number	16–18 (Table 4)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	9–14
31. Clarity of major themes	Were major themes clearly presented in the findings?	9–14
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	9–14

Appendix 2. Overview of topic lists for patients with memory complaints, significant others and general practitioners

Section	Questions
GP's interview guide	
• Usual care and (shared) decision-making process for people with memory complaints	• When a patient comes to your general practice with memory complaints, can you describe how the discussion about diagnostic testing for dementia typically unfolds? • How do you incorporate shared decision-making principles in this decision-making process? • To what agree do you believe patients and their significant other desire to be actively involved in the decision-making process on diagnostic testing for dementia? • Which factors hinder of facilitate shared decision-making on diagnostic testing for dementia?
• Expectations and considerations when starting diagnostic testing for dementia	• What are your perspectives on diagnosing dementia, both in a general practice setting and at a memory clinic? • What are your expectations and considerations when you refer patients for specialised diagnostic testing?
• Attitudes towards (early) diagnostic testing and shared decision-making	• How do you feel about early diagnosis of Alzheimer's disease? • What are advantages and disadvantages? • Can you describe how the discussion on early diagnosis of Alzheimer's disease with patients and significant others unfolds? • How important do you feel shared decision-making is therein?
Patients' and significant others' interview guide	
• Experiences with the decision-making process on diagnostic testing in general practice	• Why did you make an appointment with your GP on memory complaints? • What expectations did you have of the conversation with your GP? • Can you describe the conversation you had with your GP on your (or your significant others') memory complaints? • How did you feel about talking to your GP about your (or your significant others') memory complaints? • Can you tell what decision has been made about diagnostic testing and how was the decision made?
• Expectations and considerations in starting diagnostic testing for dementia	• What were your considerations in the decision on diagnostic testing for dementia? • What do you expect from (specialised) diagnostic testing?
• Satisfaction with the decision-making process and experienced shared decision-making	• Could you describe your role in the decision-making process on diagnostic testing for dementia? • How would you describe your level of participation in the decision on diagnostic testing for dementia? • Can you tell me about the information you have received about the benefits and harms of (specialised) diagnostic testing? • How satisfied were you with the course of the decision-making process?

Note. GP = general practitioner.

Appendix 3. Visual representation of analytic process



Separately for GPs and patients/significant others

Step 1
Open coding

Step 2
Matching open codes with deductive code groups:
1. Views on starting a diagnostic trajectory (feeling of needing to do something, beliefs on the necessity of diagnostic testing, expected outcomes of diagnostic testing)
2. Normalization or validation of symptoms
3. Support or wishes of the social network
4. Interaction with health care professionals
5. Health status
6. Societal factors

Step 3
1. Code fits with deductive code group → deductive code group kept
2. Code kind of fits with deductive code group but expands deductive code group → deductive code group renamed
3. Code does not with with deductive code group → inductive code group added

Step 4
Aggregating both inductive and deductive code group in new conceptual dimensions

Step 5
Triangulate and categorize code groups of all stakeholders to create themes

Note. Deductive code groups were derived from an integrative review on preferences for diagnostic testing for dementia (Linden I, Hevink M, Wolfs C, et al.; Understanding patients' and significant others' preferences on starting a diagnostic trajectory for dementia: An integrative review. *Aging & Mental Health* 2022:1–12.)