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Doing the Right Thing? General Practitioners' Considerations in Achieving a Timely Dementia Diagnosis

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ABSTRACT

Objectives: Timely detection and diagnosis of dementia are beneficial for providing appropriate, anticipatory care and preventing acute situations. However, initiating diagnostic testing is a complex and dynamic process that requires general practitioners (GPs) to balance competing priorities. Previously identified barriers, such as a lack of time, knowledge, and resources, may not fully represent the challenges involved in this process. Therefore, this study aimed to examine GPs' more implicit considerations on starting the diagnostic trajectory for dementia.

Methods: A qualitative study was conducted using semi-structured interviews with 14 Dutch GPs who were purposively selected through maximum variation sampling. The interview transcripts were inductively analyzed in multiple rounds by a multidisciplinary research team using thematic analysis.

Results: GPs' considerations on starting the diagnostic trajectory for dementia can be summarized in three main themes that are interconnected: (1) 'the presumed patient's willingness', that is, facing a dilemma of wanting to respect patient autonomy in cases of denial or an absence of a diagnostic request, while at the same time identifying a problem and feeling the urgency to act; (2) 'the GP's attempt not to harm', that is, balancing between not wanting to harm the patient and/or relatives with the burdensome label of dementia and with the possible negative consequences of a late diagnosis; and (3) 'time, trust, and interprofessional collaboration influence timeliness of diagnostic work-up', that is, time available for consultations, time as a diagnostic factor, GP's diagnostic confidence, and trustful physician-patient relationship.

Conclusions: This study revealed that important ethical dilemmas regarding patient autonomy and the principle of doing no harm lie behind practical GP barriers to initiating diagnostic testing for dementia. Time, trust, and interprofessional collaboration were found to facilitate GPs in determining the right decision and timing with each individual patient and their relatives. Future research could explore the value of diagnostic decision aids that explicitly involve patients and their relatives in this balancing act.

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Summary

- This study revealed that important ethical dilemmas regarding patient autonomy and the principle of doing no harm lie behind practical GP barriers to initiating diagnostic testing for dementia.
- After recognizing signs of dementia, GPs may regularly face a dilemma of wanting to respect patient autonomy in cases of denial or an absence of diagnostic request, while at the same time identifying a problem and feeling the urgency to act.
- General practitioners aim to strike a balance when deciding the optimal time to initiate diagnostic testing for dementia, weighing the concern of avoiding harm to patients and their relatives from the burdensome label of dementia against the potential negative consequences of a delayed diagnosis.
- Time, trust, and interprofessional collaboration were found to influence GPs in determining the right decision and timing with each individual patient and their relatives.

1 | Introduction

Dementia poses a global societal challenge [1]. Several benefits underscore the importance of timely detection and diagnosis of dementia. Advantages include opportunities to enhance the well-being of individuals with dementia and their families, facilitate advance care planning, prevent the use of drugs with adverse side effects, provide guidance on driving, and coordinate future care while postponing institutionalization [2, 3]. However, many individuals with dementia receive a diagnosis only at an advanced stage. Meta-analysis showed a 62% pooled rate of undetected cases, and real-world data indicated that nearly one-quarter of patients in Europe and North America have already reached the moderate stage of dementia upon diagnosis [4, 5].

In many healthcare systems, GPs are usually the first point of contact for any health-related issues [6]. This makes them well-positioned to detect dementia in two ways. Firstly, patients or their relatives may express concerns regarding memory loss to their GPs [7]. Secondly, beyond responding to direct requests, GPs are in the perfect position to identify cognitive changes during consultations for other age-related or chronic health issues [8]. Also, other healthcare professionals may report suspicions on cognitive problems to GPs, for example, when cognitive problems become apparent during hospitalization [9].

Previous studies highlighted several barriers that hinder GPs from diagnosing dementia, such as a lack of time, awareness, knowledge, or training [10–12]. However, a study of GPs' experiences emphasized that diagnosing dementia is not a one-off event where extra awareness and training will necessarily improve the GPs' ability to diagnose dementia timely [13]. It is instead an evolving process of a dynamic interplay between the patient, relatives, and the GP, in which the GP's role comprises starting a conversation, creating possibilities for ongoing conversations, and assuring that the patient and relatives are in control and safe. Shared decision-making during this process is particularly important to ensure

everyone's best interest is considered [14]. Given the complex and evolving nature of diagnosing dementia rather than it being a single consultation diagnosis, previously identified barriers presumably do not represent the full extent of challenges involved in starting diagnostic testing aimed at achieving timely dementia diagnosis [13]. Therefore, this study aimed to examine GPs' more implicit considerations on starting the diagnostic trajectory for dementia.

2 | Materials & Methods

2.1 | Study Design

This study used a qualitative design employing reflexive thematic analysis [15, 16]. We conducted semi-structured interviews to explore GPs' considerations on starting the diagnostic trajectory for dementia when suspecting dementia. This research follows an interpretivism ontology paradigm and emic epistemology, guiding our use of reflexive thematic analysis. Using reflexive thematic analysis, themes were developed through an organic and iterative process while the researchers' subjectivity was taken into consideration during immersion and reflection. This approach allows for deep engagement with data and aligns with the study's aim to explore the GPs' more implicit considerations. The study was part of the ABOARD-project: A Personalized Medicine Approach for Alzheimer's Disease [17, 18]. This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) (Supporting Information S1) [19].

2.2 | Participants and Recruitment

Between May 2022 and April 2023, Dutch GPs were invited via email or telephone by FV to participate in the interview. We approached GPs using a purposive sampling strategy to capture a broad range of perspectives and comprehensive understanding of the topic. Therefore, GPs were selected through maximum variation sampling based on work experience, gender, practice location (city and suburban/rural practices, and practices located throughout the Netherlands), practice type (solo practice run by a single GP, duo practice of two collaborating GPs, group practice), age range of practice population (relatively young/average/relatively old), and education or personal interest of the GP in dementia or elderly medicine. We used various channels to recruit GPs with diverse characteristics. One method involved contacting regional GP cooperations in the Netherlands, such as the 'Groningen Huisartsen Cooperatie', which supports general practices by facilitating collaboration among different care partners and healthcare innovation. Other channels to approach GPs were the referral platforms of an academic hospital and a general memory clinic, as well as the professional network of the research team.

2.3 | Data Collection

All interviews were conducted by FV, a physician researcher and PhD candidate who had been trained in conducting interviews.

HvZ, an experienced qualitative researcher, supervised FV. The interviews were conducted face-to-face or via secure videoconference as favored by the participant. A topic list was used to conduct the interviews (Supporting Information S2). After an introduction and explanation of the research purpose, the interview started with probes to let the participant elaborate about them being a GP, about their practice, and their experience with diagnosing dementia. The subsequent questions of the topic list were defined based on literature review, and on experiences of memory clinic clinicians and GPs in the professional network of the research team. This resulted in broad open-ended questions to inductively explore the GPs' experiences and considerations, as well as some deductive topics, to check whether we could confirm previous research findings. Overall topics included: experiences in recognizing signs of dementia, and suspecting dementia; thoughts about the decision to wait-and-see, to start diagnostic testing in primary care, or to refer for dementia diagnostics; and the needs of GPs in timely diagnosing dementia. FV conducted two pilot interviews with non-GP physicians to test the topic list, after which the wording of some questions was refined. During the interviews with participating GPs, the research team revised the topic list based on the information gathered in previous interviews and preliminary data analysis. Initially, the course of the diagnostic trajectory and reasons for referral were main topics discussed, but it became clear from the first few interviews that richer information emerged about considerations after recognizing and suspecting dementia and the timing of dementia diagnosis. The interviews lasted 50 min on average (range 40–70 min). After each interview, field notes on thoughts and comments about the interview and the perspectives of participants were reported by the interviewer. After the eleventh interview, no new concepts related to the research questions emerged in the following three interviews and data analysis, which confirmed data saturation.

2.4 | Analysis

Interviews were recorded and transcribed verbatim. A multidisciplinary research team inductively analyzed the interview transcripts in multiple rounds using reflexive thematic analysis as described by Braun and Clarke [15]. This method started by familiarization with the interview transcripts. All three researchers of the analysis team read the transcripts (FV, MvE: internist-geriatrician-PhD, and HvZ: MD PhD and an experienced qualitative researcher). The coding phase involved inductive open coding: text fragments were labeled with a code that was close to the original text. Subsequently, the codes were compared with each other, and overarching codes were defined. Thereafter, we discussed the connections between the codes and looked for explanations. FV started with the coding, and during structural meetings with the analysis team (FV, MvE, and HvZ) the transcripts and codes were critically discussed in reflexive dialog, and the codes were iteratively refined. Fieldnotes on thoughts and comments about the interviews were also considered during these discussions. For example, the fieldnotes captured reflections on the researchers' perspectives and judgments regarding what they considered right or wrong. During discussions, the analysis team paid close attention to how their

own ideas might influence the interpretation. FV, MvE, and HvZ searched for overarching themes, reviewed themes, and defined them. Subsequently, the defined themes and codes were discussed and finalized with other members of the research team (LH: geriatrician—PhD, MP: general practitioner—PhD and a qualitative research expert, and BvM: internist-geriatrician—PhD). FV made notes during these discussions and kept record of the process in memos. Atlas.ti 22 software was used to facilitate the analysis.

2.5 | Ethical Considerations

The Medical Ethics Review Board of the University Medical Center Groningen (METc UMCG) confirmed that the Medical Research Involving Human Subjects Act did not apply (reference number 2022/195). Subsequently, the medical ethics committee reviewed and approved the research protocol (reference number 202200218). Informed consent was obtained from all participants.

3 | Results

3.1 | Study Population and Context

Of 19 invited GPs, 14 GPs participated in this study (Table 1). Three of the GPs actively approached via email or telephone did not respond, and two declined to participate due to time restrictions. Eight interviews were conducted face-to-face and six online. Table 1 shows the characteristics of the participating GPs.

TABLE 1 | Characteristics of participating GPs.

Characteristics	N = 14
Age	
Years, median (range)	49 (35–65)
Gender	
Female/male	9/5
Years of experience as a GP	
Median (range)	15 (3–28)
Education or personal interest in dementia or elderly medicine	
Yes/no	3/11
Type of practice	
Solo/duo/group	1/7/6
Location of practice	
City/suburban or rural	8/6
Self-estimated age range of practice population ^a	
Relatively young/average/relatively old	4/5/5

^aGPs were asked whether they considered the population of their practice relatively young, average, or old compared to the general population of practices.

GPs described four ways in which they were prompted to suspect dementia:

- i. Patients or close relatives directly express concerns about dementia

Well, you know, people who visit me, for example, with memory complaints.

(GP 5)

- ii. A remark is made by someone in the patient's social or professional network

Or my assistant who says, "I don't think things are going well because she's asking questions that don't make sense," or the practice nurse who notices things, sees that there are glitches. Or the pharmacy that mentions something about it. So, it's really the network of people who know the patient and bring the issue to our attention; that's actually the majority of ways these issues come to light.

(GP 4)

- iii. GPs identify signs or symptoms through their own observations

One gentleman came to my office once, and I thought, hmm, you're acting a bit different than usual, something doesn't seem right here.

(GP 3)

- iv. Via a proactive detection and monitoring practice policy (e.g., assigning a practice nurse with elderly-focused training to visit frail, older patients at home for assessing and monitoring psychosomatic problems, thereby facilitating early detection of cognitive changes).

So at a certain point, we started working preventively. The practice nurse began checking in on all patients over eighty years old [...] to see how they are doing, and you can choose to do this because it does add a lot of extra work. But it also helps to prevent those crisis situations.

(GP 8)

If patients or their relatives expressed concerns about dementia during consultations (i), GPs did not experience many

difficulties initiating diagnostic evaluations. Nevertheless, GPs noted that patients showing signs of dementia rarely visit their practice for memory problems. Remarkably, GPs mentioned that if a patient, in fact, had visited them with worries about their memory and dementia, there was generally little to worry about. In contrast, if a relative shared their concerns, it was usually an indication of dementia.

If the patient comes to me alone and expresses concerns like "I think I have dementia", I think that in 9 out of 10, it is not the case. [...] But if they come in with their partner, in 9 out of 10 cases, it is indeed dementia, well, almost, or at least very close to it.

(GP 10)

Conversely, if patients or close relatives did not express their concerns (i.e., there was no direct diagnostic request), starting diagnostic testing for dementia appeared to be less self-evident. If GPs were prompted via ways (ii), (iii), or (iv), most of them faced various hurdles and considerations in determining when and whether to initiate the diagnostic trajectory.

3.2 | Considerations Influencing the Start of a Diagnostic Trajectory

Overall, we identified three overarching themes capturing considerations that may influence the GP's decision to start the diagnostic trajectory of dementia: (1) the presumed patient's willingness, (2) the GP's attempt not to harm, and (3) time, trust, and interprofessional collaboration influence timeliness of diagnostic work-up (Figure 1).

3.2.1 | The Presumed Patient's Willingness

A thoroughly discussed theme during the interviews was 'the presumed patient's willingness' (Table 2).

In a certain way, we pick up a cue and then it depends a bit on, well, on how much the patient is willing to cooperate. Of course, this is not always the case.

(GP 10)

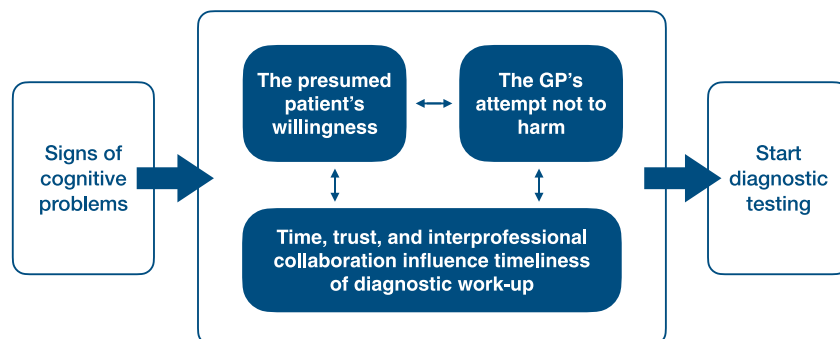


FIGURE 1 | Themes influencing the GP's decision to start the diagnostic trajectory for dementia.

TABLE 2 | Themes influencing the GP's decision to start the diagnostic trajectory for dementia.

Facilitating	<ul style="list-style-type: none"> – Request for help regarding dementia from patient and/or relative – Regular contact or home visit by PNEC – Possibility to consult ECP to visit the patient <ul style="list-style-type: none"> – Trustful physician–patient relationship – Sense of urgency among close relatives or the patient's support network – Proactive detection and monitoring practice policy <ul style="list-style-type: none"> – Normalization 	<ul style="list-style-type: none"> – Prevention of acute problems and crises <ul style="list-style-type: none"> – Anticipate care needs – Relatives can become accustomed to the diagnosis <ul style="list-style-type: none"> – Not wanting to harm with possible consequences of a late diagnosis 	<ul style="list-style-type: none"> – Feeling competent in discussing the topic dementia and diagnostic testing – Regular contact or home visit by PNEC – Possibility to consult ECP to visit the patient <ul style="list-style-type: none"> – Trustful physician–patient relationship – The ability to take time for collecting additional information and monitoring
Theme	The presumed patient's willingness	The GP's attempt not to harm	Time, trust, and interprofessional collaboration influence timeliness of diagnostic work-up
Challenging	<ul style="list-style-type: none"> – Absence of request for help regarding dementia from the patient <ul style="list-style-type: none"> – Patient denial – Gradually taking on tasks by close relatives or the patient's support network – Respect for freedom of choice (patient autonomy) 	<ul style="list-style-type: none"> – Impact of a serious and confronting diagnosis <ul style="list-style-type: none"> – Problematic and unpopular message of potential driving restriction, sometimes resulting in family discord – Concerns to harm the physician–patient relationship – Shame and stigma of dementia <ul style="list-style-type: none"> – Lack of consequences 	<ul style="list-style-type: none"> – Lack of time, knowledge, resources – No long-term or trustful physician–patient relationship

Abbreviations: ECP = elderly care physician; PNEC = practice nurse for elderly care.

GPs described facing a dilemma of identifying a problem and feeling the urgency to act, while at the same time wanting to respect patients' autonomy and right not to know.

If someone is still in the early stages and doesn't really want to know, then it's not so easy for me to say, sir, you have dementia. [...] I think because it is confrontational and because someone doesn't want to know and because someone may deny it, and, well, what should he do with this information then, he did not ask me anything.

(GP 3)

GPs observed wide variety in patient willingness to undergo diagnostic testing or discuss dementia, influenced by individual personalities, context, and dementia type.

I know that there are people who would like to be proactive about arranging things in case they are no longer able to do so because of their dementia. But I also see very big individual differences there. There

are also people whom you can't really talk to about the disease. Patients who, who really don't allow it, or... People with vascular dementia, these people often still have disease insight or awareness about their disease for a bit longer, then a conversation is possible... I find the patient population quite diverse.

(GP 12)

One GP noted that GPs are trained to act upon a request for help. Accordingly, a difficulty that most GPs mentioned was a frequent absence of such a request for help from the patient, including patients who were even denying any cognitive changes.

The person in question does not have a care request. For us as GPs, that's obviously where we need to start. We only provide care when it is requested.

(GP 2)

A few GPs emphasized the value of the patient's freedom of choice and believe that every patient has the right to choose that they do not want to know (their medical condition).

I believe that in that regard, there is a certain freedom of choice. [...] specifically explaining what the... the advantages and disadvantages could be. I always try to explain that, if, you know, there are consequences for people when they receive the diagnosis, and I do think that they should consider those before they are led in a certain direction. Well, you know, sometimes people don't see that coming either.

(GP 13)

Additionally, GPs report the risk of being dismissed if they persist when patients are unwilling. In such instances, even with a strong suspicion of dementia, GPs were not able to make a diagnosis.

Well, she always said that if she was going to get dementia, because it runs in the family, she would prefer euthanasia. And I had noticed for a while, together with her son, that her memory was declining, and things were going wrong. And at some point, we decided together to have a little test done here, and since then, she has never been back here. She now visits my colleague, luckily there are several of us here. But her son, she can't just send him away because she depends on him, but that's what she would have preferred. She considers it quite serious that I did that test, and her son too. That we did it.

(GP 2)

In certain cases, GPs justify their strategy of allowing the patient's denial to continue a little longer, while avoiding conflict. For instance, the start of diagnostic testing may be delayed if informal caregivers are still able to provide adequate support.

If it's not a problem yet because you have a caregiver or a partner who supports you, that's life [...] but well, that's also why the diagnosis also comes a bit later or too late.

(GP 2)

Some GPs described strategies to increase patient willingness. The strategies can be roughly categorized into a normalization approach and a good cop—bad cop approach. One course of normalization was the proactive detection and monitoring practice policy. As part of this proactive strategy, the Practice Nurse for Elderly Care (PNEC) could normalize the issue of dementia and cognitive testing. GPs experienced that the PNEC is in a better position to discuss cognitive changes and administer a cognitive test. The PNEC can introduce the issue more gradually during one or more home visits or as a standard part of routine assessment. GPs thought this was a better approach than them suddenly introducing the topic or a cognitive test during a brief office visit.

Or through the practice nurse, like, "Do you mind if I administer an MMSE if madam or sir agrees?" [...] then

it becomes a bit of a, you know, in a normal conversation, and it doesn't immediately become a big deal.

(GP 7)

During their consultations, GPs also employed normalization strategies to reduce the threat of the topic, for instance by reassuring patients that their goal is to keep things how they are as much as possible.

Well, I always try to get across that the aim is simply to enable you to function as independently as possible. So, it's not about locking you up or taking you away. We actually want to see how you can continue to live as well and as safely as possible in your current situation. So, trying to communicate that, that it's not so threatening.

(GP 10)

Additionally, the second strategy, the good cop—bad cop approach, aided GPs in dealing with challenges related to patient willingness. GPs mentioned they valued the possibility to consult an elderly care physician (ECP), because, in the first place, an open conversation about dementia was stimulated through visits by someone who has more time and is more of a specialist than the GP. The ECP was illustrated as someone who acts as an external and independent expert. The engagement of an ECP enables GPs to stay out of the autonomy conflict, to avoid rejection by the patient, and possible harm to the relationship.

Very often, these are questions that are suitable for the elderly care physician [...] or to deliver news that they don't want to hear, because then I don't have to do that as a GP, so that's also nice, and it helps to maintain a good relationship with the patient.

(GP 7)

Other factors that might contribute to patient willingness were a trustful physician–patient relationship and a sense of urgency by the patient's relative or someone else in the support network.

3.2.2 | The GP's Attempt Not to Harm

The theme 'The GP's attempt not to harm' reflects the balancing act GPs described between not wanting to harm with the burdensome label of dementia, while on the other hand not wanting to harm with the possible negative consequences of a late diagnosis (Table 2).

Objectively, it shouldn't matter, but emotionally, it's still a damaging label in some way for people... So, I do try to make memory problems discussable [...] But yes, there is indeed a kind of sensitivity to make it discussable and to make a diagnosis. [...] This also varies a lot from person to person. [...] So, I always try

to discuss it in that way: as long as things are going well, there's actually not much of a problem. The only potential risk we face is that something might happen later, and I can't predict what it might be, that causes a change for the patient or the support system, requiring us to do something. At that moment, it's easier if you already have a diagnosis, rather than having to make one then, and go through the diagnostic process. So, that can be an added value for both the family and the patient.

(GP 13)

GPs emphasized a diagnosis could harm a patient in several ways. First, dementia is a confronting diagnosis without curative treatment. Second, a potential driving restriction following the dementia diagnosis can impact the patient because it may lead to more reliance on their relatives.

It can lead to disagreement, but yes, that is often not the reason to refer, because often the partner sitting next to them is actually very happy that we say that [driving restriction], because they have considered it dangerous for months or even years. However, sometimes that can also be a barrier because the only person who can drive is no longer authorized to do so, so there is an immediate problem with getting around.

(GP 7)

Third, GPs highlighted that the shame and stigma surrounding dementia can be harmful.

Dementia is often a bit of a loaded subject, it has a certain stigma, and people prefer not to admit that they have dementia. [...] As long as people can manage on their own, I also don't want to give them that stigma or label unless there is real added value.

(GP 13)

However, some GPs, including those who have organized proactive detection and monitoring, perceived a timely diagnosis helps to anticipate care. Some were motivated not to harm patients and relatives by preventing acute problems and crisis situations through timely diagnosing dementia.

Of course I feel a responsibility to do something, if only for my own sake. Because you already know that this could lead to trouble, and you really want to avoid a crisis. So you prefer that these people do not wander the streets in confusion or cause any kind of trouble.

(GP 10)

The motivation to prioritize directing toward a diagnosis over patient autonomy was sometimes driven by the risk to harm that could arise from not diagnosing dementia.

If my assessment is that this person is better off not driving, then that is an additional argument for me to

guide them towards a diagnosis... If those kinds of things don't play a role, then yes, I think they have a certain choice in the matter.

(GP 13)

Moreover, as experienced by one GP, the harm could be reduced if relatives would be able to gradually grow accustomed to the diagnosis, and if they would receive counseling during a less advanced stage.

Then you also have the time to thoroughly assess everything [...] and the people around the patient need some time to get used to it, to the disease, to the idea of having dementia. At first, they don't tell anyone, and then they tell the children at some point, at least that's what you often notice. And, and that's actually better than having it hit you all at once, like a bombshell.

(GP 14)

3.2.3 | Time, Trust, and Interprofessional Collaboration Influence Timeliness of Diagnostic Work-Up

The theme 'time, trust, and interprofessional collaboration influence timeliness of diagnostic work-up' demonstrates several circumstances that help GPs starting the diagnostic trajectory (Table 2). One GP mentioned that time, as a diagnostic factor, may be beneficial for GPs. As a GP, it is relatively convenient to schedule an extra or follow-up appointment after a while, or to contact a family member for obtaining a hetero anamnesis.

There's the time factor, of course. If there are no complicating factors, you have some time to do a test, talk to a daughter, to run another test, and it doesn't have to be clear tomorrow right away.

(GP 7)

Some of the GPs trusted their own competence when it came to discussing dementia and initiating diagnostic testing. They felt confident and experienced no difficulty. This was often the case for GPs who specialized in elderly care or who worked in a practice with a relatively old patient population.

I do maximum diagnostics and that is not too complicated, I think.

(GP 2)

Several GPs mentioned a long-term and trustful physician-patient relationship to be facilitating as well. Additionally, various kinds of interprofessional collaboration were highly valued by most GPs. For instance, collaboration with a PNEC and/or ECP enables home visits. Visiting the patient at home creates a context in which they cannot present themselves better than they really are.

In the consultations [...] if something comes to light that makes me think, well, that doesn't seem to be

going quite right, or how would that work at home, then I ask our practice nurse to go visit. For example, to assess how things are going, how these people are actually managing because in the consultation room, they generally present themselves much better than they are at home.

(GP 9)

4 | Discussion

GPs wonder what is the right thing to do for patients and their relatives during the process from becoming aware of signs of dementia toward the start of the diagnostic trajectory. Three interconnected themes illustrate the GPs' considerations during this process. First, the presumed patient's willingness reflects a dilemma that GPs are facing. On the one hand, GPs try to respect patient autonomy in cases of denial or absence of a diagnostic request. At the same time, they identify a problem related to cognition and feel the urgency to act. Second, GPs try to do no harm. They attempt to find a balance between not doing harm with the burdensome label of dementia and with the possible negative consequences of a late diagnosis. Third, GPs consider time, trust, and interprofessional collaboration beneficial in initiating the diagnostic trajectory of dementia. After becoming aware of signs of dementia, these factors may facilitate the process of deciding 'what is right' for the patient and their relatives.

Our study confirms that GPs prefer and strive for a timely diagnosis of dementia [13, 20]. Timely means appropriate to the person's preferences, goals, and situation, without alluding to a certain disease stage [13, 21, 22]. We found that GPs are looking for the moment to start diagnostic testing that will cause the least harm to patients and their relatives. On the one hand, this means that GPs aim for a moment early enough to anticipate care needs before acute problems emerge. GPs in our interviews appear to be increasingly aware of the urgency of anticipating care needs because they perceive an increasing demand for dementia care. This demand may be driven by the aging population and nursing care shortages [1, 23, 24]. On the other hand, GPs try to avoid harm from a too-early diagnosis because of the lack of consequences of a formal diagnosis. This finding is consistent with the 'therapeutic nihilism' described in research [10, 25]. However, our study builds on previous findings, such as therapeutic nihilism and practical barriers, by providing insight into the underlying ethical dilemmas.

The underlying ethical dilemmas show that the GPs' considerations are based on some of the fundamental principles of the medical profession [26, 27]. One of the ethical issues that emerged in our study is respect for autonomy. GPs try to respect patients' choices to test for dementia in the early stages. At the same time, GPs also try to respect the decision of patients who choose not to start diagnostic testing, even if they have clear symptoms of dementia and limited disease insight may influence their decision. Our findings align with a study on physician's views regarding early diagnosis of Alzheimer's Disease. In this study, physicians also prioritized meeting patient's wishes when deciding about diagnostic testing [28]. A second ethical

dilemma that we identified is the avoidance of harm (the non-maleficence principle). GPs in our study considered that both diagnosing dementia too early as well as diagnosing dementia too late could be harmful. Our findings suggest that the direction of this delicate balance to avoid harm is influenced by the specific situation of the patient (e.g., the patient's willingness, their support network). Yet, the balance is also likely influenced by the GP's personal view of what constitutes the least harm. Interestingly, our study shows that the two principles of autonomy and non-maleficence can also conflict with each other. In our study, GPs regularly encounter patients who lack insight, deny their symptoms, or do not have a health request about dementia. This situation may raise the question for GPs: do I still do good by respecting freedom of choice (autonomy), even if I know that a patient might not be able to oversee this choice. When not overseeing the choice, the GP may not be able to avoid harm by the possible negative consequences of a late diagnosis. This difficult balance is supported by studies reporting a similar dilemma between these ethical principles. In another context, for example, the autonomy of individuals with dementia who wished to stay living at home could conflict with the desire of their relatives to prevent harm [29, 30].

Previous research supports our findings on time, trust and interprofessional collaboration as facilitators [10–12, 20, 31–34]. GPs indicated these factors enable the start of the diagnostic trajectory for dementia, for instance by stimulating conversation. Conversation promotes an informed and shared decision [35, 36]. The conversation of shared decision-making enables figuring out what is least harmful to an individual patient and their relatives, in their specific situation. To start the conversation about dementia, GPs in our study highly valued collaboration with practice nurses and ECPs. Gibson et al. studied practice nurses' perceptions of their role in dementia care [31]. Practice nurses mentioned they were better positioned to overcome the dementia stigma than the GP because of their different, less threatening, role. They possess intuition skills to determine the appropriate timing to address memory issues. Also, nurses spend more time with patients, which enables them to gain a comprehensive understanding of patients' interactions, thought processes, and behavior [31]. Additionally, close collaboration between local healthcare professionals has been shown to contribute to improved expertise in dementia diagnostics and improved dementia care [32]. This supports our finding of GPs highly valuing interprofessional collaboration. The facilitators time and trust found in our study align with the barriers lack of time, training, and knowledge that have been frequently reported in previous research [10–12, 20, 33, 34].

This study provides valuable implications for improving the timing of dementia diagnosis. To improve the accuracy and timing of diagnosis, previous research has largely focused on developing advanced diagnostic tools, such as imaging and fluid biomarkers [37]. Our study, however, once again highlights the need to expand this focus to the stage before diagnostic testing. The challenge of timely diagnosis lies not just in the accuracy and accessibility of diagnostic tests, but also in initiating the diagnostic trajectory at all. Our findings indicate the need to pay attention to the role of ethical dilemmas prior to the start of the diagnostic trajectory. These dilemmas should be explicitly discussed with patients, their relatives, and, where appropriate,

other healthcare professionals involved. As national dementia guidelines inconsistently address these issues, it may be beneficial to include ethical considerations in guidelines or to give them extra attention in the GPs' training [38]. Also, during the GPs' training program, more attention could be paid to addressing a difficult topic when there is no direct help request from a patient. Our findings suggest that it would be beneficial to learn strategies for discussing and dealing with symptom denial or limited insight to enlarge GPs' trust. Besides the GPs' trust, our findings underline the importance of a trustworthy physician–patient relationship because it enables explicit discussion of the difficult topic of dementia. We found that starting the conversation about dementia may on the other hand potentially harm the GP–patient relationship. Accordingly, our research highlights the facilitating role of an ‘external, independent expert’ in discussing dementia and diagnostic testing. Therefore, we underline promoting and financing interprofessional collaboration. This includes working with practice nurses, and for example within the Dutch healthcare system, collaboration with the ECP [31, 39]. Finally, future prospective research should investigate the value of diagnostic decision aids in facilitating the complex decision-making process for individuals with cognitive symptoms, their relatives, and GPs [40]. These types of tools may help to explicitly involve patients and their relatives in the balancing act, which currently seems to be often an implicit assessment by GPs [14]. In the Netherlands, a patient decision aid has been introduced to help individuals decide whether to initiate diagnostic testing for dementia [41]. Yet, the impact of such a decision aid on, for example, patient and family satisfaction, the timeliness of dementia diagnoses, and the impact on the number of diagnoses remains to be examined.

Some limitations and strengths of this study should be noted. First, the study was conducted among Dutch GPs of the same ethnicity (Caucasian). Although this research provides valuable insights for the international field, the results may not fully apply to other healthcare systems. Second, the interview transcripts were not coded by a second independent researcher. Instead, FV coded the interviews based on continuous and iterative discussions with the analysis team (HvZ and MvE). All three of them read the transcripts. Still, this may have affected the reliability of our findings because both the interviews and coding were conducted by FV. However, the meaning and interpretation of transcripts and codes were extensively discussed with a multidisciplinary team consisting of researchers, and both specialist and generalist clinicians (investigator triangulation). One strength of our study is the richness of data collected, both due to the duration and depth of the interviews. This enabled us to explore the considerations behind previously reported barriers to diagnosing dementia in general practice. Additionally, except for ethnic diversity, a heterogeneous population of GPs was included in this study through purposive sampling, including those who had no affinity for dementia. This contributed to the study's transferability.

5 | Conclusion

This study revealed that ethical dilemmas regarding patient autonomy and the principle of doing no harm lie behind the

practical GP barriers to initiating diagnostic testing for dementia. While research into dementia diagnosis has largely focused on developing advanced diagnostic tools to enable timely diagnosis, our findings highlight the need to support GPs in determining the right decision and timing with each individual patient and their relatives. Time, trust, and interprofessional collaboration were found to facilitate this decision-making process. Future research could explore the value of diagnostic decision aids that explicitly involve patients and their relatives in the balancing act.

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Ethics Statement

The Medical Ethics Review Board of the University Medical Center Groningen (METc UMCG) confirmed that the Medical Research Involving Human Subjects Act did not apply (reference number 2022/195). Subsequently, the medical ethics committee reviewed and approved the research protocol (reference number 202200218).

Consent

Informed consent was obtained from all participants.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Permission to Reproduce Material From Other Sources

The authors have nothing to report.

References

1. M. Prince, A. Wimo, M. Guerchet, G.-C. Ali, Y.-T. Wu, and M. Prina, *World Alzheimer Report 2015. The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends* (London: Alzheimer's Disease International, 2015).
2. J. L. Liss, S. Seleri Assunção, J. Cummings, et al., “Practical Recommendations for Timely, Accurate Diagnosis of Symptomatic Alzheimer's Disease (MCI and Dementia) in Primary Care: A Review and Synthesis,” *Journal of Internal Medicine* 290, no. 2 (2021): 310–334, <https://doi.org/10.1111/joim.13244>.
3. M. Prince, R. Bryce, and C. Ferri, *World Alzheimer Report 2011. The Benefits of Early Diagnosis and Intervention* (London: Alzheimer's Disease International (ADI), 2011).

4. L. Lang, A. Clifford, L. Wei, et al., "Prevalence and Determinants of Undetected Dementia in the Community: A Systematic Literature Review and a Meta-Analysis," *BMJ Open* 7, no. 2 (2017): e011146, <https://doi.org/10.1136/bmjopen-2016-011146>.
5. C. W. Ritchie, C. M. Black, R. K. Khandker, et al., "Quantifying the Diagnostic Pathway for Patients With Cognitive Impairment: Real-World Data From Seven European and North American Countries," *Journal of Alzheimer's Disease* 62, no. 1 (2018): 457–466, <https://doi.org/10.3233/jad-170864>.
6. B. Starfield, L. Shi, and J. Macinko, "Contribution of Primary Care to Health Systems and Health," *Milbank Quarterly* 83, no. 3 (2005): 457–502, <https://doi.org/10.1111/j.1468-0009.2005.00409.x>.
7. I. Linden, M. Hevink, C. Wolfs, M. Perry, C. Dirksen, and R. Ponds, "Understanding Patients' and Significant Others' Preferences on Starting a Diagnostic Trajectory for Dementia: An Integrative Review," *Ageing & Mental Health* 27, no. 5 (2022): 1–12, <https://doi.org/10.1080/13607863.2022.2084505>.
8. G. Livingston, J. Huntley, A. Sommerlad, et al., "Dementia Prevention, Intervention, and Care: 2020 Report of the Lancet Commission," *Lancet* 396, no. 10248 (2020): 413–446, [https://doi.org/10.1016/s0140-6736\(20\)30367-6](https://doi.org/10.1016/s0140-6736(20)30367-6).
9. E. L. Reynish, S. M. Hapca, N. De Souza, V. Cvorov, P. T. Donnan, and B. Guthrie, "Epidemiology and Outcomes of People With Dementia, Delirium, and Unspecified Cognitive Impairment in the General Hospital: Prospective Cohort Study of 10,014 Admissions," *BMC Medicine* 15, no. 1 (2017): 140, <https://doi.org/10.1186/s12916-017-0899-0>.
10. T. Koch and S. Iliffe, "Rapid Appraisal of Barriers to the Diagnosis and Management of Patients With Dementia in Primary Care: A Systematic Review," *BMC Family Practice* 11, no. 1 (2010): 52, <https://doi.org/10.1186/1471-2296-11-52>.
11. F. Petrazzuoli, S. Vinker, T. H. Koskela, et al., "Exploring Dementia Management Attitudes in Primary Care: A Key Informant Survey to Primary Care Physicians in 25 European Countries," *International Psychogeriatrics* 29, no. 9 (2017): 1413–1423, <https://doi.org/10.1017/s1041610217000552>.
12. R. Balogh, N. Imre, E. Papp, et al., "Dementia in Hungary: General Practitioners' Routines and Perspectives Regarding Early Recognition," *European Journal of General Practice* 26, no. 1 (2020): 7–13, <https://doi.org/10.1080/13814788.2019.1673723>.
13. S. A. Dhedhi, D. Swinglehurst, and J. Russell, "'Timely' Diagnosis of Dementia: What Does it Mean? A Narrative Analysis of GPs' Accounts," *BMJ Open* 4, no. 3 (2014): e004439, <https://doi.org/10.1136/bmjopen-2013-004439>.
14. I. Linden, C. Wolfs, M. Hevink, C. Dirksen, R. Ponds, and M. Perry, "Why to Test for Dementia: Perspectives of Patients, Significant Others and General Practitioners," *Age and Ageing* 53, no. 1 (2024): afad251, <https://doi.org/10.1093/ageing/afad251>.
15. V. Braun and V. Clarke, "Using Thematic Analysis in Psychology," *Qualitative Research in Psychology* 3, no. 2 (2006): 77–101, <https://doi.org/10.1191/1478088706qp063oa>.
16. V. Braun and V. Clarke, *Conceptual and Design Thinking for Thematic Analysis* (US: Educational Publishing Foundation, 2022), 3–26.
17. W. M. van der Flier, M. E. de Vugt, E. M. A. Smets, M. Blom, and C. E. Teunissen, "Towards a Future Where Alzheimer's Disease Pathology Is Stopped Before the Onset of Dementia," *Nature Aging* 3, no. 5 (2023): 494–505, <https://doi.org/10.1038/s43587-023-00404-2>.
18. M. A. E. Dreves, A. C. van Harten, L. N. C. Visser, et al., "Rationale and Design of the ABOARD Project (A Personalized Medicine Approach for Alzheimer's Disease)," *Alzheimer's Dementia* 9, no. 2 (2023): e12401, <https://doi.org/10.1002/trc2.12401>.
19. A. Tong, P. Sainsbury, and J. Craig, "Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups," *International Journal for Quality in Health Care* 19, no. 6 (2007): 349–357, <https://doi.org/10.1093/intqhc/mzm042>.
20. L. Sannemann, T. Müller, L. Waterink, et al., "General Practitioners' Attitude Toward Early and Pre-Dementia Diagnosis of AD in Five European Countries—A MOPEAD Project Survey," *Alzheimer's Dementia* 13, no. 1 (2021): e12130, <https://doi.org/10.1002/dad2.12130>.
21. M. Devine, "Patient Centred Diagnosis of Dementia: We Must Listen to Patients' Wishes," *British Medical Journal* 359 (2017): j5524, <https://doi.org/10.1136/bmj.j5524>.
22. D. Brooker, J. La Fontaine, S. Evans, J. Bray, and K. Saad, "Public Health Guidance to Facilitate Timely Diagnosis of Dementia: Alzheimer's COoperative Valuation in Europe Recommendations," *International Journal of Geriatric Psychiatry* 29, no. 7 (2014): 682–693, <https://doi.org/10.1002/gps.4066>.
23. Rijksoverheid, "Report on Project About Waiting Lists and Capacity Nursing Homes," [in Dutch] (2020), <https://www.rijksoverheid.nl/documenten/publicaties/2020/06/10/voortgangsrapportage-project-wachttijsten-en-capaciteit-verpleeghuizen>.
24. European Commission, "Long-Term Care Report – Trends, Challenges and Opportunities in an Ageing Society," Vol II, Country Profiles (2021), <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&puId=8396>.
25. A. Bradford, M. E. Kunik, P. Schulz, S. P. Williams, and H. Singh, "Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors," *Alzheimer Disease and Associated Disorders* 23, no. 4 (2009): 306–314, <https://doi.org/10.1097/wad.0b013e3181a6bebc>.
26. S. H. Miles, *The Hippocratic Oath and the Ethics of Medicine* (Oxford, NY: Oxford University Press, 2004).
27. T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*. 8th ed. (New York, NY: Oxford University Press, 2019).
28. K. Tromp, M. Smedinga, E. Richard, M. Perry, and M. H. N. Schermer, "Views on Early Diagnosis of Alzheimer's Disease Among Dutch Physicians: A Qualitative Interview Study," *Journal of Alzheimer's Disease* 79, no. 2 (2021): 917–927, <https://doi.org/10.3233/jad-200884>.
29. K. L. Smebye, M. Kirkevold, and K. Engedal, "Ethical Dilemmas Concerning Autonomy When Persons With Dementia Wish to Live at Home: A Qualitative, Hermeneutic Study," *BMC Health Services Research* 16, no. 1 (2016): 21, <https://doi.org/10.1186/s12913-015-1217-1>.
30. Å. Gjellestad, T. Oksholm, H. Alvsvåg, and F. Bruvik, "Autonomy Conquers All: A Thematic Analysis of Nurses' Professional Judgement Encountering Resistance to Care From Home-Dwelling Persons With Dementia," *BMC Health Services Research* 22, no. 1 (2022): 749, <https://doi.org/10.1186/s12913-022-08123-x>.
31. C. Gibson, D. Goeman, A. Hutchinson, M. Yates, and D. Pond, "The Provision of Dementia Care in General Practice: Practice Nurse Perceptions of Their Role," *BMC Family Practice* 22, no. 1 (2021): 110, <https://doi.org/10.1186/s12875-021-01467-z>.
32. A. Richters, M. S. Nieuwboer, M. G. M. Olde Rikkert, R. J. F. Melis, M. Perry, and M. A. van der Marck, "Longitudinal Multiple Case Study on Effectiveness of Network-Based Dementia Care Towards More Integration, Quality of Care, and Collaboration in Primary Care," *PLoS One* 13, no. 6 (2018): e0198811, <https://doi.org/10.1371/journal.pone.0198811>.
33. S. Cahill, M. Clark, C. Walsh, H. O'Connell, and B. Lawlor, "Dementia in Primary Care: The First Survey of Irish General Practitioners," *International Journal of Geriatric Psychiatry* 21, no. 4 (2006): 319–324, <https://doi.org/10.1002/gps.1464>.
34. S. Turner, S. Iliffe, M. Downs, et al., "General Practitioners' Knowledge, Confidence and Attitudes in the Diagnosis and

Management of Dementia,” *Age and Ageing* 33, no. 5 (2004): 461–467, <https://doi.org/10.1093/ageing/afh140>.

35. G. Elwyn, D. Frosch, R. Thomson, et al., “Shared Decision Making: A Model for Clinical Practice,” *Journal of General Internal Medicine* 27, no. 10 (2012): 1361–1367, <https://doi.org/10.1007/s11606-012-2077-6>.

36. R. Stalnikowicz and M. Brezis, “Meaningful Shared Decision-Making: Complex Process Demanding Cognitive and Emotional Skills,” *Journal of Evaluation in Clinical Practice* 26, no. 2 (2020): 431–438, <https://doi.org/10.1111/jep.13349>.

37. P. Scheltens, B. De Strooper, M. Kivipelto, et al., “Alzheimer’s Disease,” *Lancet* 397, no. 10284 (2021): 1577–1590, [https://doi.org/10.1016/S0140-6736\(20\)32205-4](https://doi.org/10.1016/S0140-6736(20)32205-4).

38. H. Knüppel, M. Mertz, M. Schmidhuber, G. Neitzke, and D. Strech, “Inclusion of Ethical Issues in Dementia Guidelines: A Thematic Text Analysis,” *PLoS Medicine* 10, no. 8 (2013): e1001498, <https://doi.org/10.1371/journal.pmed.1001498>.

39. T. Vrijmoeth, A. Wassenaar, R. Koopmans, M. S. Nieuwboer, and M. Perry, “Generalist-Specialist Collaboration in Primary Care for Frail Older Persons: A Promising Model for the Future,” *Journal of the American Medical Directors Association* 23, no. 2 (2022): 288–296.e3, <https://doi.org/10.1016/j.jamda.2021.12.016>.

40. I. Linden, C. Wolfs, M. Perry, et al., “Implementation of a Diagnostic Decision Aid for People With Memory Complaints and Their General Practitioners: A Protocol of a Before and After Pilot Trial,” *BMJ Open* 11, no. 6 (2021): e049322, <https://doi.org/10.1136/bmjopen-2021-049322>.

41. Nederlands Huisartsen Genootschap, Keuzehulp: Wel of Geen Onderzoek Naar Dementie? accessed December 14, 2023, <https://www.thuisarts.nl/keuzehulp/wel-of-geen-onderzoek-naar-dementie>.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.