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RESEARCH ARTICLE

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Exploring diagnostic strategies for memory complaints in older adults: A retrospective general practice database study

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Abstract

Objectives: For older people who worry about their memory, their general practitioner (GP) is often the first healthcare professional they turn to. This study aims to increase knowledge of GPs' daily practice on diagnostic strategies for patients who present themselves with memory complaints and/or worries about dementia for the first time in general practice and to explore associations of patients' characteristics with these strategies.

Method: Retrospective observational study using electronic patient records from patients presenting with memory complaints between 2012 and 2019. The patient records are derived from a Dutch primary care registration network. The decision on diagnostic strategy was extracted and categorized as (1) wait and see, (2) diagnostic testing in primary care, or (3) referral. Patient characteristics (gender, age, general practice, level of comorbidities, chronic polypharmacy, and the number of consultations on memory complaints), fear of developing dementia, and information on why the first consultation on memory complaints was scheduled were extracted.

Results: A total of 228 patients were included. Most patients were cared for within primary care, either for further primary care diagnostics (56.1%) or because a wait-and-see strategy was pursued (14.9%). One-third (28.9%) of patients were referred. Differences between diagnostic strategies in patient characteristics, fear of developing dementia, or reason for first consultation between these diagnostic strategies were not found, nor were these variables predictive of referral.

Conclusion: Most Dutch patients with memory complaints and/or worries about dementia who seek help from their GP for the first time are cared for in the primary care setting for the following 6 months. The lack of association between included patient characteristics and diagnostic strategies highlights the complexity of the decision-making process on diagnostic testing for dementia in general practice.

KEYWORDS
dementia, electronic health records, general practice, memory, referral and consultation

Key points

- Most Dutch patients who seek help for memory complaints from their general practitioner (GP) for the first time are not referred for specialized diagnostic testing, which underlines the crucial and gatekeeper role GPs play in the management and care for this patient group.
- Previous qualitative research indicates that GPs consider patient characteristics important in decisions on diagnostic trajectories for memory complaints. Retrospective data from the studied electronic patient records, however, indicates that patient characteristics such as age and comorbidity do not differ between diagnostic strategies nor are they predictive for referrals.
- Further unraveling of the complex decision-making process for diagnostic testing for dementia is needed to facilitate timely dementia diagnoses.

1 | INTRODUCTION

Memory complaints are common in older adults[1] and could be early signs of cognitive decline and possibly (future) dementia. As society ages increasingly, more older people become worried about their memory and seek assessment.[2] Early assessment of memory complaints has been advocated by some because early diagnosis provides opportunities to plan one's future care and life. Moreover, future interventions could potentially delay the progression of the disease.[3,4] Early assessment could also provide reassurance that dementia is not present (yet). However, a diagnosis may also be burdensome, anxiety-provoking, stigmatizing, and even harmful when it raises false expectations regarding treatment.[5] The decision when to assess memory complaints and possibly diagnose dementia is considered a preference-sensitive decision.[6–8] That is, some patients may prefer (early) diagnostic testing for an opportunity for (future) treatments, whereas others delay or defer diagnostic testing and do not actively seek help because they believe it will be beneficial for their quality of life.[9,10] By taking these preferences into account a timely diagnosis (i.e. the moment in time the patient and significant other perceive they can benefit most from a diagnosis) can be achieved.[11]

If older adults that worry about their memory do seek help, general practitioners (GPs) are generally the first healthcare professionals to be contacted. In the Netherlands, GPs are gatekeepers to specialist care, and a specialist can be seen only after a referral by a GP. According to the practice guideline of the Dutch College of GPs, GPs are encouraged to diagnose dementia themselves.[12] Most GPs favor a timely dementia diagnosis over an early diagnosis.[7] GPs experience challenges in starting a diagnostic trajectory for dementia, such as a lack of time during consultations, particularly in older patients with multiple health issues, and a lack of knowledge and skills in diagnosing dementia.[13,14]

When deciding on diagnostic strategies, in the case of memory complaints, GPs appear to take patients' characteristics into account. Qualitative research suggests that they feel less need to pursue a formal dementia diagnosis in their oldest patients or in patients who already receive a lot of care for other diseases when a diagnosis would not impact prognosis or quality of care.[15] These results were found in qualitative interviews and self-report measures.[13–15] More objective insights into GPs' decisions on diagnostic strategies of patients with memory complaints are lacking. Increasing the knowledge of GPs' diagnostic strategies may help in facilitating timely dementia diagnosis and care for older adults with memory complaints who may worry about dementia. Therefore, this study aims to investigate GPs' diagnostic strategies (i.e., wait-and-see, start primary care diagnostics, referral) in the first 6 months after patients present themselves for the first time in daily practice with memory complaints, and to explore associations of patients' characteristics with these strategies.

2 | METHODS

2.1 | Design and setting

We performed a retrospective observational study using data from the Family Medicine Network (FaMe-net). FaMe-net is a primary care registration network containing routinely collected data, affiliated with the Radboud university medical centre in Nijmegen[16] (Box 1). We had online access to the electronic patient records of three urban general practices in the area of Nijmegen, with two practices in an area consisting of old villages that became part of the city of Nijmegen. We lacked data from the other FaMe-net practices, as their patient records could only be accessed when physically present in the general practice, which was not feasible during the study period because of the COVID-19 pandemic. We followed the RECORD-Recommendations (Reporting of studies Conducted using Observational Routinely-collected health Data) in reporting the results.[17]

BOX 1 The Family Medicine Network (FaMe-net)

In 2018, this network consisted of 26 GPs in seven different general practices throughout the Netherlands, including approximately 32.000 patients.[16] Electronic patient records of patients in the participating practices are automatically used unless patients actively dissent (opt-out procedure). GPs affiliated with the FaMe-net systematically register all encounters with their patients using the International Classification of Primary Care (ICPC) system.[18,19] Within this system, each encounter is registered with an episode of care. An episode of care is defined as an individual health problem that starts at the first encounter and is completed at the final encounter linked to that health problem. Within an episode of care, all diagnostic actions and interventions are registered, including history, physical examination, diagnostic tests, medical advice, referrals, and medical correspondence from hospitals.[20] Furthermore, for each consultation, GPs register a reason for encounter (RFE). The RFE is defined as the first complaint, symptom, or request the patient mentions when consulting the GP.[21]

2.2 | Patient selection

Patients were considered for inclusion if they had a new P20 (memory disturbances) or P70 (dementia) episode or RFE ICPC code between 2012 and 2019, were 60 years or older, and memory complaints were explicitly discussed at first presentation (Table 1). The age limit of 60 years was chosen to exclude patients with young onset dementia as the dynamics of these diagnostic trajectories are usually different than in older patients.[22]

2.3 | Data collection

For each patient included, we extracted all consultations on memory complaints until their episode ended from the electronic patient record using a predefined data extraction form (Table S1). These could be follow-up consultations with a P20 or P70 ICPC or RFE code, but those with other ICPC or RFE codes were extracted if memory complaints or worries about dementia were also discussed. All follow-up consultations after the first P20 or P70 ICPC or RFE code, until the end of the episode, were manually checked by the data extractors to check whether memory complaints or worries about dementia were discussed in consultations with other ICPC or RFE codes. We aimed to capture the initial decision-making regarding diagnostic strategies when patients (or their significant others) present with memory complaints and/or worries about dementia for the first time. To focus on this initial phase, we used consultations up to a maximum of 6 months after the first consultation on memory complaints in this study (e.g., exclude consultations that took place because patients returned due to worsening memory complaints over time). Data extraction was performed by the first author (IL) and a trained research assistant (FF). Each 25th case was extracted by both IL and FF and possible differences were discussed, to ensure concurrent data extraction. Fourteen cases were extracted by both data extractors. In 10 of these cases (71%) the data extractors extracted the case in exactly the same way. Discrepancies were related to the interpretation of inclusion criteria for patients or consultations. During the data extraction process, three researchers (IL, FF, and MP (GP)) met regularly to discuss issues that arose from the cases. MP also checked 10 random cases to ensure cases were extracted according to the data extraction sheet. No issues arose from this check by MP. The final data extraction form contained five different sections with the following variables:

2.3.1 | Patient characteristics

Gender, age (at the first encounter on memory complaints), general practice (1, 2, or 3), level of comorbidities, chronic polypharmacy, and the number of GP consultations addressing memory complaints.

To calculate the level of comorbidities for each patient, the Charlson Comorbidity Index (CCI) score was used,[23] including all chronic diseases registered up to the last extracted consultation. CCI scores range between 0 and 30, with higher scores indicating more comorbidity.[23] Dementia is also part of the CCI, but since dementia is a possible outcome in this study it was not included in the CCI calculation.

TABLE 1 Inclusion and exclusion criteria.

Inclusion	Exclusion
- P20 or P70 episode or RFE ICPC code used for memory complaints at the age of 60 or older	- P20 code used for confusion, hallucinations, and transient global amnesia
- Patient, significant other or GP were worried about memory complaints	- The diagnostic process took place without the involvement of the GP (i.e. between specialist referral in a hospital for example)
- Worries about memory complaints were discussed by either the patient or a significant other with the GP	- P20 code used for the results of elderly health screening for research purposes
	- The electronic patient record did not provide enough information to extract the course of the diagnostic process

Abbreviation: GP, General Practitioner.

Polypharmacy was defined as the use of at least five different medicines (according to the Anatomical Therapeutic Chemical (ATC) classification system[24]) simultaneously in 1 year. Chronic use is defined as at least four prescriptions per ATC code in 1 year with a minimum of 6 months difference between the first and the last prescription. When patients met these criteria in the year of their first P20/P70 encounter, they were classified as having chronic polypharmacy.

2.3.2 | Reason for first consultation

Notes in the RFE fields with P20/P70 classifications related to reasons the schedule an appointment on memory complaints were categorized as (1) patients' worries about memory, (2) significant others' worries about the patients' memory, (3) health care professionals (HCP)' worries about the patients' memory, or (4) other reason not related to memory complaints (i.e., consultations not scheduled for memory complaints but for example on physical complaints, or monitoring consultations for depression, diabetes, or cardiovascular diseases).

2.3.3 | Fear of developing dementia

Patients or significant others who expressed a fear of developing dementia as noted by the GP in one of the included consultations were classified as "expressed fear" (yes/no).

2.3.4 | Decisions on diagnostic strategies

The decisions on the GPs' diagnostic strategy were categorized as (1) wait-and-see/no explicit strategy, (2) primary care diagnostics, or (3) referral for specialized diagnostic evaluation. Primary care diagnostics included the administration of a Mini-Mental State Examination (MMSE) test, laboratory tests, history taking by a significant other, or other memory tests or questionnaires. When the MMSE test was administered, the patient's score was extracted. In case patients were referred after diagnostic workup in primary care, they were categorized in the referral category. The diagnostic strategy decision was derived from the patients' last consultation record of the episode. If patients had consultations related to memory complaints outside the 6-month study window, the decision from the last consultation within the 6-month study period was used.

2.3.5 | Diagnosis

If patients were diagnosed either in primary care or after referral, their diagnosis was extracted categorized as (1) Dementia (not further specified/likely mixed form) (2) Alzheimer's Disease (3) Vascular Dementia (4) Mild Cognitive Impairment (MCI) or (5) Other forms of dementia (e.g., Frontotemporal Dementia (FTD) or Lewy Body Dementia) (6) Other (non-dementia) diagnosis.

2.4 | Data analysis

First, we used descriptive statistics to analyze the frequencies of each diagnostic strategy and patient characteristics. Differences between the decision categories regarding patient characteristics were studied using one-way ANOVA, Kruskal-Wallis, or chi-square tests with a two-sided alpha of 0.05. Post-hoc comparisons were performed with Bonferroni corrections.

Next, we examined the associations between patient characteristics and the decision to refer (to specialized diagnostic evaluation) versus not to refer (only primary care diagnostics). In a binary logistic regression with the decision to refer being the dependent variable and patient characteristics, reason for first consultation, and fear of dementia being independent variables, odds ratios and 95% confidence intervals were calculated. Intraclasscorrelation (ICC) of the intercept-only model was calculated to determine the necessity of a clustered random intercept model.[25] Backward elimination was used to examine the significance of each variable in the model.[26] All variables were assessed for collinearity. Last, to study the role of primary care diagnostics outcomes in the decision to refer, we compared referred and not-referred patients with an administered MMSE test in primary care. Independent samples *t*-tests and chi-square tests were used to study differences in patient characteristics in this subset of patients.

3 | RESULTS

3.1 | Patient characteristics

Between 2012 and 2020, a total of 345 patients had a first episode of P20 or P70, 228 of which met the inclusion criteria (Figure 1). The included patients were distributed across the three participating general practices as follows: 40.8% (practice 1), 27.2% (practice 2), 32.0% (practice 3). Patient characteristics did not differ between the practices (Table S2). Included patients had a mean age of 78.2 years (range: 60–100) at first presentation. Most of the patients were female (57.2%) and lived independently in their own homes (94.4%). The rest (5.6%) of the patients lived in nursing homes or assisted living.

3.2 | Decision categories

After the initial consultation, most patients underwent diagnostic testing either in primary care (56.2%) or after referral (28.9%). In

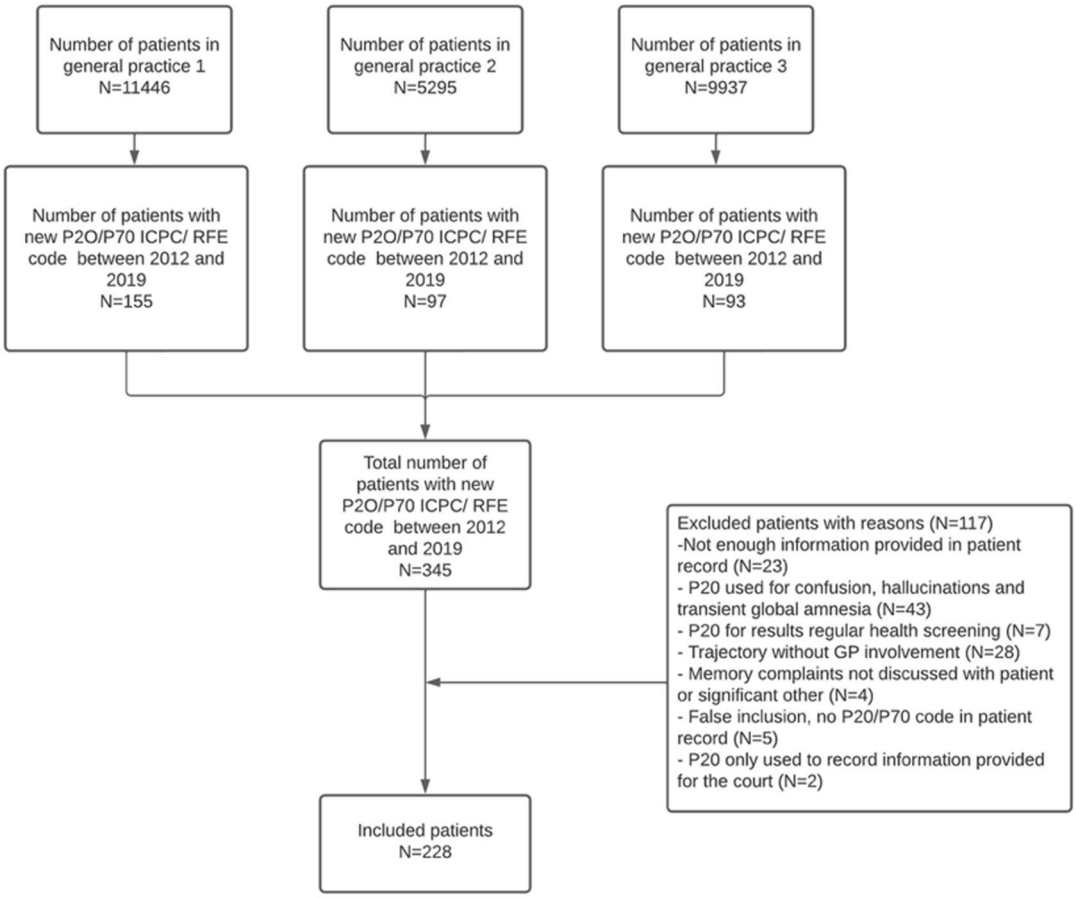

FIGURE 1 Flowchart of patient inclusion.

the other patients, a wait-and-see strategy was pursued (14.9%). Age and gender did not differ between the decision categories (Table 2).

3.3 | Reason for first consultation

Patients often first presented memory complaints in a consultation they scheduled for other complaints (32.5%), for example, physical complaints, or in monitoring consultations for depression, diabetes, or cardiovascular diseases. Furthermore, patients had a consultation on memory complaints because of their own worries (28.5%) or because of those of a significant other (26.8%). In a minority (12.3%) consultation was initiated because an HCP was worried. This did not differ between the decision categories.

3.4 | Number of consultations

On average, patients had two consultations about their memory complaints (range 1–5) in 6 months. Patients who had a diagnostic work-up (either in primary care or after referral) had more consultations than patients with a wait-and-see approach ($p < .001$, $p = .01$). For most patients (75%), the episode on memory complaints ended within the 6-month study window.

3.5 | Level of comorbidities

The mean CCI score in the sample was 1.21 ($SD = 1.51$). More than half of the included patients (54.8%) had at least one comorbid disease next to (worries about) memory complaints. Comorbidity levels did not differ between patients in the decision categories.

3.6 | Chronic polypharmacy

A quarter of patients (23.2%) had chronic polypharmacy during the period they visited their GP because of memory complaints. The use of chronic polypharmacy did not differ between decision categories.

3.7 | Fear of developing dementia

For most patients (85.5%), GPs did not register fear of developing dementia. Fear of developing dementia did not differ between decision categories.

TABLE 2 Characteristics of the entire sample and patients per decision category.

	Total (n = 228)	To wait-and-see (n = 34, 14.9%)	Primary care diagnostics (n = 128, 56.2%)	Referral (n = 66, 28.9%)	Overall group differences p-value	Primary care diagnostics–referral differences p-value
Age, mean (SD)	78.2 (8.49)	76.83 (8.7)	79.0 (8.80)	77.3 (7.66)	0.172	0.127
Female, n (%)	130 (57.0%)	18 (52.9%)	74 (57.8%)	38 (57.6%)	0.873	0.975
Comorbidity, mean (SD)	1.2 (1.5)	1.1 (1.3)	1.36 (1.7)	1.0 (1.1)	0.647	0.371
Polypharmacy, n (%)	53 (23.2%)	4 (11.8%)	35 (27.3%)	14 (21.2%)	0.144	0.352
Fear to develop dementia, n (%)	33 (14.5%)	5 (14.7%)	19 (14.8%)	9 (13.6%)	0.974	0.821
Number of consultations, mean (SD)	2.1 (1.1)	1.3 (0.6)	2.3 (1.00)	2.1 (1.1)	<0.001*	0.137
Reason for first consultation, n (%)					0.382	0.265
Worries patient	65 (28.5%)	13 (38.2%)	32 (25.0%)	20 (30.3%)		
Worries significant other	61 (26.8%)	7 (20.6%)	41 (32.0%)	13 (19.7%)		
Worries HCP	28 (12.3%)	3 (8.8%)	14 (10.9%)	11 (16.7%)		
Other reason not related to memory complaints	74 (32.5%)	11 (32.4%)	41 (32.0%)	22 (33.3%)		

Note: To detect overall group differences, a one-way analysis of variance was performed for continuous variables or Kruskal-Wallis rank tests when the assumptions for one-way analysis of variance were not met. To detect differences between patients who had diagnostic testing in primary care and patients who were referred, independent-sample t-tests were performed for continuous variables or the Mann-Withney U tests when the assumptions for independent-samples t-tests were not met. Chi-square tests were performed for categorical or dichotomous variables. The fourth reason for first consultation category "other reason not related to memory complaints" comprised of reasons for consultations related to physical complaints or monitoring consultations for depression, diabetes, or cardiovascular diseases).

Abbreviation: HCP, Health care professional.

3.8 | Decision to refer

Univariate analyses showed no significant differences in patient characteristics between referred patients and not-referred patients (Table 2). ICC was 0.0141 indicating 1.41% of variability lies between the three general practices which justify the use of a level-1 multiple binary logistic regression. The multiple logistic regression model did not identify any of the patient characteristics to be predictive of referral (Table 3). Backward elimination did not result in a better-fitting model.

Subsequent analyses of patients with an administered MMSE test (n = 137) showed that 34.8% of patients had an MMSE test before being referred. MMSE scores did not differ between referred patients (M = 24.6, SD = 3.5) and not-referred patients (M = 24.5, SD = 4.6), t (135) = −0.12, p = 0.91. However, in referred patients, HCPs were more often worried than in not-referred patients (X^2(1) = 8.06, p=.005). Referred patients (Mdn = 3.00) had more consultations than patients who were not referred (Mdn = 2.00, U = 1786.0, p = .004). Other differences in patient characteristics were not found.

3.9 | Diagnosis

Within 6 months after first presentation, 34.2% of the patients received a diagnosis. Most diagnosed patients were diagnosed after referral (67.9%), 32.1% were diagnosed in general practice. Patients who were diagnosed in general practice were all diagnosed with dementia (not further specified). Patients diagnosed after referral were diagnosed with dementia (not further specified/likely mixed forms) (40.4%), Alzheimer's disease (17.3%), Vascular dementia (3.8%), MCI (25.0%), other diagnosis (i.e., depression, anxiety, stress) (5.8%), or their diagnosis was still unclear (7.7%). Other forms of dementia (e.g., FTD or Lewy Body Dementia) were not registered.

TABLE 3 Results binary logistic regression on patient characteristics and referral.

	General practice–referred		
	ß (SE)	OR	95% CI
Intercept	2.05 (1.76)	3.93	
Age	−0.03 (0.02)	0.97	[0.94–1.02]
Gender (ref: male)	0.04 (0.31)	1.04	[0.55–1.94]
Comorbidity	−0.20 (0.12)	0.82	[0.64–1.03]
Polypharmacy	−0.31 (0.37)	0.73	[0.35–1.52]
Fear to develop dementia	0.03 (0.49)	0.97	[0.37–2.54]
Number of consultations	−0.12 (0.16)	0.89	[0.65–1.21]
Reason for first consultation (ref: other)			
Worries patient	−0.16 (0.46)	0.85	[0.35–2.09]
Worries significant other	−0.54 (0.43)	0.58	[0.25–1.36]
Worries HCP	0.43 (0.51)	1.54	[0.58–4.14]

Note: None of the results were statistically significant, p-values were therefore not displayed. The fourth reason for first consultation category "other reason not related to memory complaints" comprised of reasons for consultations related to physical complaints or monitoring consultations for depression, diabetes, or cardiovascular diseases).

Abbreviation: HCP, Health care professional.

4 | DISCUSSION

This retrospective observational study provided insight into diagnostic strategies in general practice for older adults with memory complaints and/or worries about dementia. Findings indicated that most patients who had a first consultation on memory complaints were not referred to secondary care by their GP, either because further diagnostic procedures were performed in the general practice setting (56.2%) or because a wait-and-see strategy was pursued (14.9%). One-third (28.9%) of patients were referred for specialized diagnostic evaluation within the predefined time horizon of 6 months. The finding that most patients with memory complaints and/or worries about dementia receive care in the primary care setting, underlines the crucial and gatekeeper role that Dutch GPs play in the management and support of this patient group.

Earlier qualitative studies[15] indicated that GPs felt less need to refer older patients for specialized diagnostic evaluation, whereas younger patients were more likely to be referred. GPs tend to take a holistic approach in older patients with multiple co-existing health problems, in which dementia is viewed in a spectrum of conditions for which specialized diagnostic evaluation would not improve the patient's quality of life.[27] Our findings seem, however, not consistent with these studies as patient characteristics such as age, comorbidity, and chronic medication use did not differ between diagnostic strategies. None of these variables could predict referral. It should, however, be noted we only included patients above 60 years of age. Multiple studies demonstrate that GPs' referral decisions are affected by a complex mix of patient, physician, and health care system structural characteristics.[28,29] Factors that might be considered more "subtle" such as patient, significant other, or GP preferences, GPs' knowledge, and experience, as well as contextual aspects specific to individual patients or within the healthcare system, could play a more significant role in referral decisions than previously reported in qualitative studies on diagnostic strategies for dementia.

One-third of the patients in our study (32.5%) discussed their memory complaints during appointments that were initially intended for other health concerns. This may imply that patients often find it difficult to raise the topic of perceived memory decline, which is also found in previous research.[30] In another third (26.8%) of patients, a consultation was scheduled because of significant others worried about the patient's memory. This emphasizes the crucial role played by significant others in the early stages of recognizing dementia symptoms. Significant others are key informants in the pre-diagnostic phase of dementia because they are often the first ones to recognize

early signs and can provide crucial information on the onset of symptoms.[31] In our study, however, worries of a significant other as a reason to visit the GP for the first time were not associated with the diagnostic strategy. This finding suggests that while worries expressed by significant others can serve as a motivator for seeking help, it may not by itself importantly influence the eventual choice for a specific diagnostic strategy. This finding illustrates the already mentioned complexity of the decision-making process, in which identifying key predictors for diagnostic strategies can be difficult because of its' highly individualized and context-dependent nature.

This study has strengths and limitations that are worth discussing. To our knowledge, this is the first study analyzing GPs' decisions on diagnostic strategies for memory complaints using electronic patient records. Previously, this subject has been studied using self-reported or qualitative measures.[13–15] We used routinely collected primary care data, from which the accuracy and completeness depend on the text written by GPs in the electronic patient files. This approach may have resulted in missing more implicit wait-and-see approaches as GPs may not record all their suspicions or discussions of cognitive problems that emerge implicitly. Yet, GPs who participate in this registration network are trained in registering medical data properly.[16] Our results however should be interpreted with caution. First, we were only able to include data from three general practices in one urban geographical area which may not be representative of the general population of patients with memory complaints in general practice. In comparison with other Dutch primary care registries, our sample contains relatively more older patients, ICPC P20 is less often registered but is comparable in gender distribution,[32,33] comorbidity, and polypharmacy levels.[34,35] Second, our sample size is relatively small, which may have resulted in an underpowered regression analysis. Associations between patient characteristics and diagnostic strategies should therefore be interpreted with caution. Related to this sample size, we categorized GPs' diagnostic strategies into three groups. This categorization was aimed at facilitating the exploration of potential associations between diagnostic strategies and patient characteristics. However, a more detailed approach could have been taken by for example, categorizing patients who were referred after diagnostic testing in general practice separately. A larger sample size would have allowed us to create more detailed diagnostic strategy groups that better mirror practices observed in everyday general practice. Additionally, to explore differences between referred patients and not-referred patients after primary care diagnostics, their MMSE score was used as a proxy of the primary care diagnostics outcome as this was the only suitable primary care diagnostic measure in our data for analysis. Although conducting an MMSE for further primary care diagnostics is in line with the Dutch primary care guideline,[12] the guideline also recommends complementing the MMSE with history taking with a significant other, laboratory tests, and a physical examination. Results of these measures are, however, not captured in our analysis. To further unravel this complex decision-making process ideally a large prospective study is conducted in which, next to patient characteristics, more subtle factors such as patients' preferences, GPs' characteristics, knowledge, and attitudes are included. These insights could be used to stimulate more explicit (shared) decision making possibly with the use of decision aids.[36] This could contribute to more timely dementia diagnoses, which could increase the quality of care, prevent unnecessary referrals, and therewith potentially reduce healthcare costs.[37] In summary, our findings imply that most Dutch older patients who visited their GP because they, their significant others, or HCPs were worried about their memory are managed in the primary care setting within 6 months Patient characteristics such as age and indications of the patients' health alone are not necessarily key factors in this complex decision-making process on diagnostic strategies according to general practice database data.

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CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

Data routinely collected by the FaMe research network was submitted for review to the local ethical committee, and they declared that formal judgment was not required according to the Dutch law (number: 2020-6871).

PATIENT CONSENT STATEMENT

Patients are extensively informed about including their health-related information in FaMe-Net and are offered the opportunity to opt out of FaMe-Net.

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SUPPORTING INFORMATION

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

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