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Documentation of shared decision-making in diagnostic testing for dementia in Dutch general practice: A retrospective study in electronic patient records

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ABSTRACT

Objective: To explore (1) documentation of shared decision-making (SDM) in diagnostic testing for dementia in electronic patient records (EPR) in general practice and (2) study whether documentation of SDM is related to specific patient characteristics.
Methods: In this retrospective observational study, EPRs of 228 patients in three Dutch general practices were explored for the documentation of SDM elements using Elwyn's model (team talk, option talk, decision talk). Patient characteristics (gender, age, comorbidities, chronic polypharmacy, the number of consultations on memory complaints) and decision outcome (wait-and-see, GP diagnostics, referral) were also extracted.
Results: In EPRs of most patients (62.6 %), at least one SDM element was documented. Most often this concerned team talk (61.6 %). Considerably less often option talk (4.3 %) and decision talk (12.8 %) were documented. SDM elements were more frequently documented in patients with lower comorbidity scores and patients with a relatively high number of consultations. Decision talk was more frequently documented in referred patients.
Conclusion: Patients' and significant others' needs, goals, and wishes on diagnostic testing for dementia are often documented in EPRs.
Practice implications: Limited documentation of option and decision talk stresses the need for future SDM interventions to facilitate timely dementia diagnosis.

1. Introduction

As public awareness around dementia increases, more older people ask for cognitive assessment by a specialist [1,2]. Early assessment of cognitive complaints and a possible early dementia diagnosis can be beneficial because it provides opportunities to plan one's future life and care [3] and it provides time to decide on one's future financial, legal, and medical issues while a person still has mental capacity [4,5]. Early assessment is also perceived beneficial because it can provide reassurance that dementia is not present (yet) [6]. Furthermore, a diagnosis is

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often a prerequisite to arranging adequate care [7]. New opportunities for earlier diagnosis of Alzheimer's disease based on biomarkers are growing and finding their way to clinical practice [8,9]. However, in light of the lack of disease modifying interventions, the question arises as to whether an early diagnosis is beneficial for every patient [10]. Table 1 displays arguments for and against early diagnosis of dementia. At the same time, it is common for older adults to not look for help until symptoms are already significantly impacting daily functioning [11].

The timing of starting diagnostic testing for dementia is thus a complex decision for general practitioners (GPs), who are usually the first healthcare professionals contacted when people worry about their memory. Starting (too) early with an unchangeable prognosis of dementia might be burdensome and anxiety-provoking [13,14], whereas starting (too) late may result in lack of sufficient care and support. GPs, therefore, aim for a timely dementia diagnosis, i.e. at the moment in time the patient and their significant other perceive they can benefit most from a diagnosis [15]. A timely-diagnosis thus is importantly preference-based [16] which underlines the need for shared decision-making (SDM) in the process of starting diagnostic testing for dementia [17]. In SDM, advantages and disadvantages of dementia diagnosis can be weighed based on personal values and contexts of patients and their families [18]. GPs are in the position to play a key role in the initiation of the SDM process on diagnostic testing for dementia, and in the Netherlands they are encouraged to do so by the general practice Dementia guideline [19]. However, patients experience their involvement in this decision-making process as limited and GPs may miss opportunities to facilitate patient engagement [20,21].

Documentation of care and care-related decisions including patient preferences, beliefs, and values is considered a vital part of providing (person-centered) healthcare [22,23] and is thought to support SDM [24,25], as it gives legitimacy to patient perspectives, makes the patient-provider interplay transparent, and facilitates continuity in care [26]. Due to EPRs' semi-structured nature, GPs have the opportunity to document information they value such as their patients' personal needs and considerations. However, documentation in EPRs on patients' psychosocial concerns and details of the clinical communication appears to be limited [27,28], and evidence on SDM approaches in preference-sensitive decision settings in general practice EPR documentation is lacking [29]. This study therefore aimed to explore the documentation of the decision-making process of diagnostic testing for dementia, to determine whether EPRs reveal an SDM approach to this decision.

Taking an SDM approach has been thought to be facilitated or hindered by various patient characteristics. The presence of cognitive impairment, being in poor health and older age have been reported to hinder SDM [30]. As these patient characteristics are common in patients with worries about dementia, the relationship between these characteristics and SDM documentation was further explored.

Table 1
Arguments for and against early dementia diagnosis [12].

Arguments *for* early dementia diagnosis	Arguments *against* early dementia diagnosis
Facilitate planning for the future	Risk of causing emotional distress and anxiety; avoiding maleficence
Psychological benefit to person with dementia and/or family members and carers	Inability of person with dementia to understand and/or retain the diagnosis
Maximise opportunity for patient to contribute to the management of their own dementia	No perceived benefits, or perceived costs outweigh perceived benefits
Person's 'right to know'	Person's right 'not to know'
Maximise treatment possibilities	Lack of robust evidence of improvements to well-being from strategies aimed at earlier diagnosis
Obtain access to second opinion	Potential risk of 'over-diagnosis'
Facilitate access to patient support services	Poor access to necessary specialists and/or support services
Patient is already aware of problems and wishes to know	Stigma associated with the diagnosis of dementia
	Diversion of resources away from activities of proven value

2. Methods

2.1. Research design and setting

This was a retrospective observational study using data from the Dutch Radboudumc Family Medicine Network (FaMe-net). FaMe-net is a primary care registration network, affiliated with the Radboud university medical center in Nijmegen [31] (Box 1). We studied data of three general practices in the area of Nijmegen. We followed the RECORD-Recommendations (Reporting of studies Conducted using Observational Routinely-collected health Data) in reporting the results [32].

2.2. Sample

Patients were considered for inclusion in this study if they presented for the first time with memory complaints (i.e., a new P20 (memory disturbances) or P70 (dementia) episode or Reason for Encounter (RFE) ICPC code) between 2012 and 2020 and were 60 years or older at the first consultation (Table 2). The age limit of 60 years was chosen to exclude patients with young onset dementia as the dynamics of these pre-diagnostic trajectories are usually different than in older patients [36]. Patients were excluded if (1) ICPC P20 was used for confusion, hallucinations, and transient global amnesia, (2) the diagnostic process took place without the involvement of the GP (in a hospital setting for example), (3) ICPC P20 code used for the results of elderly health screening for scientific purposes, or (4) the EPR did not provide information on the course of the diagnostic process.

2.3. Data extraction

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 (Appendix A). 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 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 six 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. During the data extraction process, three researchers (IL, FF, and MP) met regularly to discuss issues that arose from the cases.

2.3.1. Shared decision-making

Each consultation included was explored for the documentation of SDM elements (team, option, decision) in the free text notes written by the GP. Using the SDM model of Elwyn et al. (2017) a data extraction guide was created. Elwyn's SDM model [37] is a three-talk model of shared decision-making that depicts conversational steps. The steps are initiated by providing support when introducing options, followed by strategies to compare and discuss trade-offs before deliberation based on

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 [31]. 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 [33,34]. 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 [35].

Table 2
Data extraction protocol derived from the Shared Decision-Making model by Elwyn et al. [37].

SDM element	Definition of element	Short task phrase of element provided by Elwyn et al. (2017)	Concrete components to look for in the electronic patient record
Team talk	Work together, describe choices, offer support, and ask about goals	*'Let's work as a team to make a decision that suits you best'*	1. Wishes, goals, needs, fears, and cognitions of the patient 2. Involvement of a significant other in the decision-making process (i.e., wishes or needs of the significant other are noted) 3. Indication that the patient is made aware that there is a choice
Option talk	Discuss alternatives using risk communication principles	*'Let's compare the possible options'*	1. Indication that the patient is offered at least two options in the decision-making process 2. Indication that the advantages and disadvantages of options are discussed with the patient
Decision talk	Get to informed preferences, make preference-based decisions	*'Tell me what matters most to you for this decision'*	1. Indication that a decision is made in which the patient's wish or opinion is considered 2. Patient considerations in the decision made are noted

Note. SDM = Shared decision-making. Each SDM element was scored on a 3-point scale, 0 = not documented (none of the concrete components of the element scored), 1 = somewhat documented (1 concrete component of the element present), 2 = well documented (2 or 3 concrete components of the element).

informed preferences. The steps are not necessarily consecutive but can be circular. The guide was created during multiple meetings with the researchers involved in coding the free text notes (IL, MP, and CW). One involved researcher is an experienced GP with dementia expertise and one researcher is an experienced clinical neuropsychologist, which contributes to investigator triangulation and enhance credibility of the coding approach [38]. Similar to other studies on person-centred documentation in EPRs [28], the data extraction guide was iteratively created and pilot tested on 25 EPRs. After consensus, per step, concrete components were defined to identify in the EPR text (Table 2). Each consultation was coded by two researchers (IL and MP or CW). As this was an exploratory study and the data extraction guide was iteratively created, inter-coder reliability was not tested. A consensus approach was taken to enhance reliability of the coding [39]. Differences in coding for each EPR were discussed with all coders and the coding was adopted after discussion and agreement. Illustrative examples of SDM documentation were collected to support results.

2.3.2. Patient characteristics

Gender, age, general practice (1, 2, or 3), number of consultations within the six-month time window, comorbidity level, chronic polypharmacy, and data about the decision for a diagnostic strategy for memory complaints were extracted from EPRs.

To calculate the level of comorbidities for each patient, the Charlson Comorbidity Index (CCI) score was used [40], including all chronic diseases registered up to the last extracted consultation. CCI scores range between 0 and 30, with higher scores indicating more comorbidity [40]. 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.

Polypharmacy was defined as the use of at least five different medicines (according to the Anatomical Therapeutic Chemical (ATC) classification system) [41] simultaneously within one year. Chronic use is defined as at least four prescriptions per ATC code in one 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.

The GPs' diagnostic strategy was categorized as (1) wait-and-see, (2) primary care diagnostics, or (3) referral for specialized diagnostic evaluation, e.g., a memory clinic. Primary care diagnostics could include the administration of a Mini-Mental State Examination (MMSE) test, laboratory tests, history taking by a significant other, or other memory tests or questionnaires. In case patients were referred after diagnostic workup in primary care, they were categorized in the referral category.

2.4. Data analysis

The EPR of patients was the unit of analysis to assess SDM documentation. This means that the calculation of SDM documentation was based on all consultations included for each patient, rather than SDM documentation being calculated separately for each consultation. We used descriptive statistics to analyze the frequency of each SDM element, SDM overall (at least one SDM element documented in the EPR), the complete SDM process (documentation of all three SDM elements, i.e., team talk, option talk, and decision talk) and patient characteristics. Differences between the patients for whom SDM was (not) documented regarding patient characteristics were studied using independent samples t-tests, Mann-Whitney U tests, or chi-square tests with a two-sided alpha of 0.05. For 3 × 2 contingency tables for chi-square tests, post hoc testing based on adjusted residuals and Bonferroni corrections for multiple testing were performed [42,43].

3. Results

Between 2012 and 2019, a total of 345 patients had a first episode of

P20 or P70. Of them, 228 met the inclusion criteria. For 17 patients (7.5%), we found no clue that the diagnosis of dementia was a conversation topic, instead their (or their significant others') main concerns were related to arranging care considering the existing memory complaints. As our main research question was focused on SDM in deciding on diagnostic testing, these patients were excluded from the main analysis and analyzed separately (Fig. 1).

3.1. Main findings

The patients included in the main analysis were distributed across the three participating general practices as follows: 41.2% (practice 1), 27.0% (practice 2), and 31.8% (practice 3). Patient characteristics did not differ between the practices, except for comorbidity level (Appendix B). Patients had a mean age of 77.6 years (range: 60–100) at first consultation. Most patients were female (55.0%) and lived independently in their own home (91.0%). The rest (9%) of the patients lived in nursing homes or assisted living. Patients had on average two consultations on memory complaints ($M = 2.04$, $SD = 1.07$, range 1–5) within the time window of the study, 23.7% chronically used medication and 59.2% had at least one comorbid disease next to memory complaints (M=1.21, SD=1.54).

Of the 211 patients with consultations on memory complaints, 132 (62.6%) had at least one consultation in which one or more SDM elements were documented (Table 3). *Team talk* (61.6%) was most often documented of all three SDM elements. *Option talk* (4.3%) and *Decision talk* (12.8%) were documented less frequently (Table 4). Practices did not differ in frequency of SDM documentation (Appendix C).

Table 3
Degree of shared decision-making elements regarding diagnostic testing for dementia in electronic patient records.

		Not documented N (%)	*Somewhat documented N (%)*	*Well documented N (%)*
SDM element	Team talk	81 (38.4)	113 (53.6)	17 (8.1)
	Option talk	202 (95.7)	8 (3.8)	1 (0.5)
	Decision talk	184 (87.2)	23 (10.9)	4 (1.9)

Note. Each SDM element was scored on a 3-point scale, 0 = not documented (none of the concrete components of the element scored), 1 = somewhat documented (1 concrete component of the element present), 2 = well documented (2 or 3 concrete components of the element)

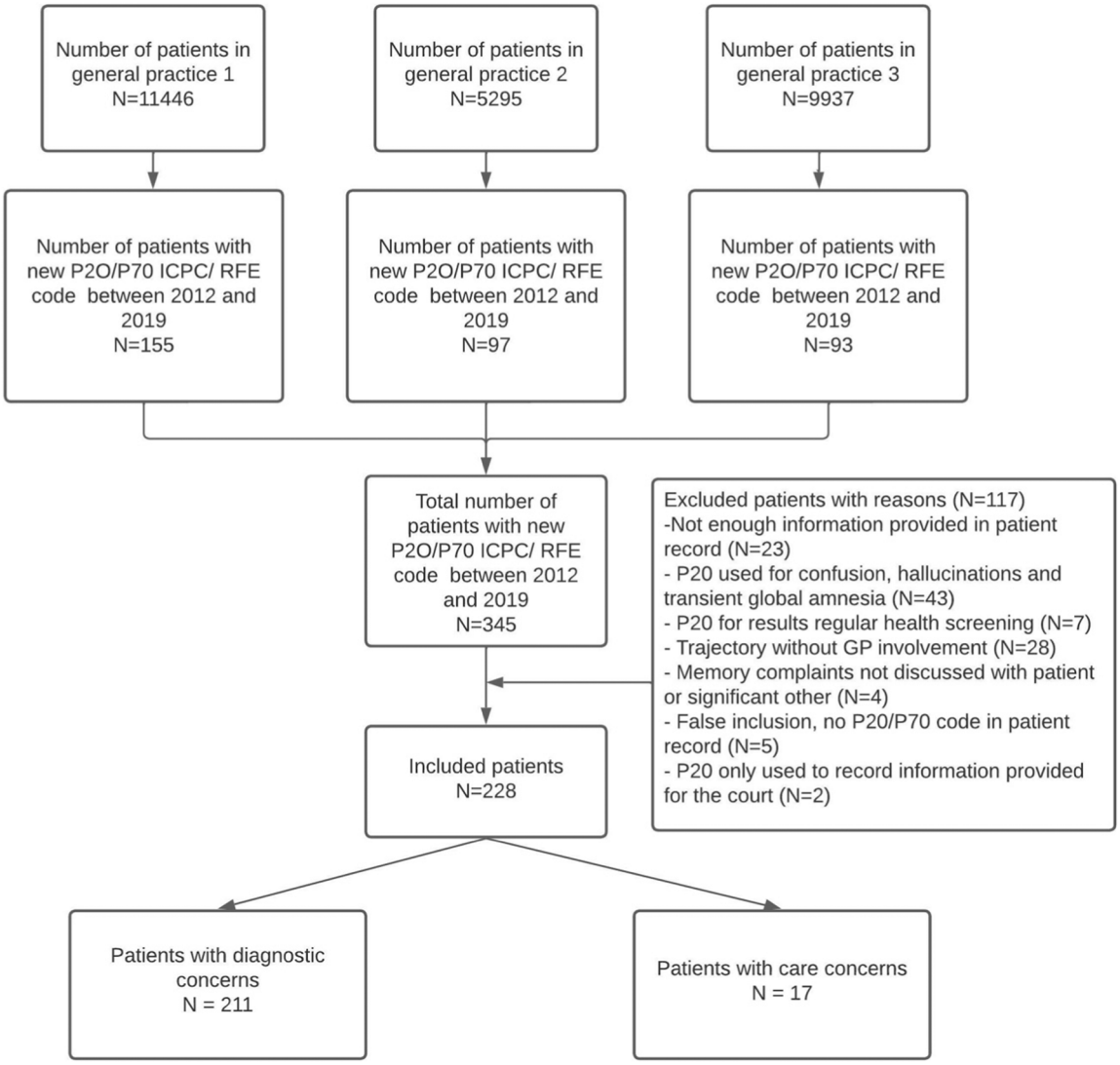

Fig. 1. Flowchart patient inclusion.

Table 4
Documentation of (combinations of) shared decision-making elements in electronic patient records and corresponding number of consultations.

	Total		Practice 1		Practice 2		Practice 3	
(combinations of) SDM elements	**No. of patients (%)**	**No. of consultations (%)**	**No. of patients (%)**	**No. of consultations (%)**	**No. of patients (%)**	**No. of consultations (%)**	**No. of patients (%)**	**No. of consultations (%)**
Team, option, decision talk	3 (1.4%)	11 (2.6%)	0 (0.0%)	0 (0.0%)	1 (1.8%)	3 (2.5%)	2 (3.0%)	8 (5.9%)
Team, option talk	6 (2.8%)	13 (3.0%)	1 (1.1%)	2 (1.1%)	3 (5.3%)	6 (5.0%)	2 (3.0%)	5 (3.7%)
Team, decision talk	22 (10.4%)	59 (13.7%)	8 (9.2%)	30 (17.1%)	7 (12.3%)	15 (12.4%)	7 (10.4%)	14 (10.3%)
Team talk	99 (46.9%)	221 (51.3%)	46 (52.9%)	93 (53.1%)	29 (50.9%)	70 (57.9%)	24 (35.8%)	58 (42.9%)
Option, decision talk	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Option talk	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Decision talk	2 (1.0%)	3 (0.7%)	1 (1.1%)	2 (1.1%)	1 (1.8%)	1 (0.8%)	0 (0.0%)	0 (0.0%)
None	79 (37.4%)	124 (28.7%)	31 (35.6%)	48 (27.4%)	16 (28.1%)	26 (21.5%)	32 (47.8%)	50 (37.0%)
Total	211 (100%)	431 (100%)	87 (100%)	175 (100%)	57 (100%)	121 (100%)	67 (100%)	135 (100%)

Note. Patients only appear once in this table therefore patients for whom a combination of SDM elements is documented are not included in the main element count (e.g., team, option, or decision talk separately)

3.1.1. Team talk

Team talk was most frequently identified because of the documentation of patients' wishes, needs, or goals or those of their significant others. Sometimes only the wish or need of a patient was documented (i.e., the patient wants further diagnostic testing) whereas in other cases considerations for a patient's need or wish were also documented. Examples included;.

> *'[….]Patient has no need for diagnostic testing. Recommended information GP.info [website of the Dutch College for General Practitioners]. Patient will read it, in case needed she will schedule a new consultation within 6 weeks to discuss it. Explanation that there is no simple diagnostic test for Alzheimer's' [EPR Female patient, age 79]*

> *'Son is also present, familiar forgetfulness which is not increasing [….]. Especially the son fears it will be too late to arrange another living situation and if it turns out to be Alzheimer's medication may be possible. An MMSE test will be arranged to further monitor the situation. No evidence of severe dementia right now' [EPR Female patient, age 78]*

Indications that the patient or significant other was explicitly offered a choice (Team Talk concrete element 3) were not documented in the included EPRs.

3.1.2. Option talk

Option talk was documented in 4.3% of the EPRs regarding diagnostic testing for dementia. SDM documentation entailed the discussion of one option (e.g., conducting an MMSE in general practice or referral), but the discussion of at least two options was sparsely documented. Examples included;.

> '*[…] Conversation, outlined options, continuing diagnostic testing here or referral, opts for the memory clinic'* [EPR Female patient, age 62]

3.1.3. Decision talk

Decision talk was documented in 12.8% of the EPRs. In most of these cases, the GP documented that the patient was involved in the decision made, only in a few cases also the patient's considerations in the decision made were documented. Examples were:

> *'Thinks he is doing well, considerably confused a while ago [….] Diagnostic testing at the geriatric department offered, would not like that, prefers the old age psychiatry clinic. Will be registered for [old age psychiatry clinic]'* [EPR Male patient, age 88]

3.1.4. The complete SDM process

In only three patients (1.4%), all three elements of SDM were documented in their consultations on memory complaints (Table 4). These elements were for all three patients documented in the same consultation note. A larger group of patients (25 patients, 11.8%) had team talk as well as decision talk in their consultations on deciding on diagnostic testing for dementia. In the majority (22 patients, 88%) of these patients, team talk, and decision talk were documented in the same consultation. For example:

> *'Would like a referral to the neurologist to see if she has (an early stage form of) dementia […] Wants to know if she has dementia to arrange matters timely. [.]We discussed to start with an MMSE test here, if the test result is good, we will monitor it the coming years in primary care. In case needed, in due course referral'* [EPR Female patient, age 68]

3.1.5. Patient characteristics associations with SDM

Patients with SDM elements documented in their EPR did not differ in age and gender from patients who did not have SDM elements (together or analysed separately) documented in their EPR (Table 5). Differences in option talk were not calculated as the proportions were too low.

Patients who had SDM elements in their EPR had on average more consultations than patients without SDM elements in their EPR. Similar differences were found when analysing team talk and decision talk separately. Furthermore, patients with SDM elements in their EPR had on average fewer comorbidities than patients without SDM elements in their EPR. These differences were also found when analysing team talk. For decision talk, differences in comorbidities were not found. Differences in polypharmacy were not found for SDM elements overall and for team talk and decision talk separately (Table 5).

The diagnostic strategy followed (wait-and-see, diagnostics in general practice, or referral) was not related to the documentation of SDM elements overall nor to the documentation of team talk (Table 6). However, there was an association between decision talk and the followed diagnostic strategy. Post hoc testing indicated that decision talk was more often documented in patients who were referred compared to patients who had a wait-and-see strategy or diagnostic testing in primary care ($p < .001$).

3.2. SDM in patients with a focus on arranging care

Of the 228 patients, 17 patients (7.5%) had a first GP consultation on memory complaints in which arranging care was the main concern. These patients were on average 85.1 years old (SD=5.35), 82.4% were female, 17.6% chronically used medication, had a mean comorbidity score of 1.29 (SD=1.16), and had on average two consultations on memory complaints within six months ($M = 2.24$, $SD = 0.97$). They were older than patients whose main concerns were regarding diagnostic testing t (23.0)= −5.31, $p < .001$, and were more often female (X^2 (1, $N = 228$) = 4.81. $p = .03$, $\Phi = -.15$). Differences in comorbidity and

Table 5
Patient characteristics per SDM element.

Variables	Overall SDM				Team talk				Option talk				Decision talk			
	Mean (SD)	t/Z	p-value	Effect size	Mean (SD)	t/Z	p-value	Effect size	Mean (SD)	t/Z	p-value	Effect size	Mean (SD)	t/Z	p-value	Effect size
Age																
SDM not documented	76.66 (8.56)	−1.26	0.211	0.18	76.54 (8.52)	−1.45	0.15	0.20	77.58 (8.37)	-	-	-	77.75 (8.62)	0.64	0.53	0.14
SDM documented	78.17 (8.37)				78.26 (8.38)				78.06 (10.67)	-	-	-	76.63 (7.28)			
Comorbidity level																
SDM not documented	1.53 (1.66)	−2.44	**0.015**	0.32	1.54 (1.65)	−2.65	**0.008**	0.35	1.23 (1.55)	-	-	-	1.22 (1.56)	−0.26	0.79	0.07
SDM documented	1.02 (1.44)				1.00 (1.44)				0.78 (1.30)	-	-	-	1.11 (1.37)			
Consultations																
SDM not documented	1.57 (0.70)	4.90	**< .001**	0.80	1.57 (0.69)	5.02	**< .001**	0.81	2.01 (1.06)	-	-	-	1.95 (1.01)	3.21	**0.001**	0.66
SDM documented	2.33 (1.15)				2.34 (1.15)				2.67 (1.12)	-	-	-	2.70 (1.24)			
	N (%)	X^2	p-value	Effect size	N (%)	X^2	p-value	Effect size	N (%)	X^2	p-value	Effect size	N (%)	X^2	p-value	Effect size
Gender (female)																
SDM not documented	39 (49.4)	1.61	0.21	0.09	40 (49.4)	1.66	0.20	0.09	112 (55.4)	-	-	-	103 (56.0)	0.58	0.45	0.05
SDM documented	77 (58.3)				76 (58.5)				4 (44.4)	-	-	-	13 (48.1)			
Polypharmacy (yes)																
SDM not documented	21 (26.6)	0.58	0.45	0.05	21 (25.9)	0.36	0.55	0.04	45 (22.3)	-	-	-	45 (24.5)	0.46	0.50	0.05
SDM documented	29 (31.3)				29 (22.3)				5 (55.6)	-	-	-	5 (18.5)			

Note. To detect differences in patient characteristics between patients with SDM documentation in their patient records and patients without SDM documentation, independent-sample t-tests were performed for continuous variables or the Mann-Whitney U tests when the assumptions for independent-samples t-tests were not met. Chi-square tests were performed for categorical or dichotomous variables. *Cohen's d* was used as effect size for continuous variables and *Phi* for categorical or dichotomous variables. Differences in patient characteristics and option talk were not computed as the proportion of option talk was too low. Significant p-values are highlighted in bold.

number of consultations were not found. Differences in polypharmacy were not calculated because assumptions for the chi-square test were not met. Most patients stayed in primary care either because diagnostic testing was conducted (n = 11) or because a wait-and-see strategy was pursued (n = 4). Only two patients were eventually referred for specialized diagnostic testing. In cases where diagnostic testing was conducted, this was in all cases initiated by the GP or practice nurse to either test the level of cognitive impairment in light of arranging care or because diagnostic testing was a condition for arranging appropriate care.

For the majority of the patients (n = 15), elements of SDM were documented in their consultations. This percentage was higher than in patients whose main concerns were regarding diagnostic testing (X^2 (1, $N = 228$) = 4.53, $p = .03$, $\Phi = .14$). Team talk was most often documented (15 patients, 88.2%). This percentage was also higher than in patients whose main concerns were regarding diagnostic testing (X^2 (1, $N = 228$) = 4.81, $p = .03$, $\Phi = .15$). GPs often documented the patients' wish to refrain from involvement of health care professionals (e.g., starting home care). Team talk was also often documented because significant others discussed or were involved in arranging care.

For example:

> *'Daughter comes to inform me about her mother's declining memory […] Mum does not want any help- no home care- daughter sees no possibilities to arrange care right now, but wants me to be informed'* [EPR Female patient, age 89]

Option talk was not documented in consultations on arranging care. Decision talk was documented in the EPR of three patients and in all cases concerned documentation of the patient's involvement in the decision of starting care.

For example:

> *'[…] Asked if he agrees with contacting home care to assist him with dressing and other things in his household. He finds that difficult but understands it's to make things easier for him. Discussed that home care is not to do everything for him, but to stimulate that he can do as much as possible on his own. That sounded better for him. We agreed that I'll make an appointment with home care to schedule an introductory meeting'* [EPR Male patient, age 79]

Differences in option- and decision talk were not calculated because assumptions for the chi-square test were not met.

4. Discussion and conclusion

4.1. Discussion

This study explored the documentation of SDM in EPRs of patients who visited their GP with memory complaints for the first time and the association between patient characteristics and SDM documentation. We found that over 60% of the EPRs contained notes with SDM documentation. Most often the patients' (or significant others') needs, wishes, or goals (i.e., team talk) were documented. This finding aligns with qualitative research on deciding on diagnostic testing for dementia in which GPs value their patients' wishes and needs [12]. Previous research on person-centered documentation showed limited information on patients' goals or psychosocial concerns in EPRs [27,28]. However, in a study on person-centered documentation in the context of behavioral change and self-management the level of person-centered documentation was similar to our study. Contexts in which patient goals, context, or considerations are considered important by health care professionals might thus make person-centered documentation more likely [44]. In observational studies regarding SDM, the elicitation of patients' wishes and needs is not often observed. Instead health care professionals are often observed to facilitate questions or reflection [45]. This might imply that patients and significant others actively voice their goals and needs when worried about dementia or GPs actively initiate discussion

Table 6
Descriptive statistics for SDM components and diagnostic strategies.

	Diagnostic strategy			
Variable	**Wait and see, N (%)**	**Primary care diagnostics, N (%)**	**Referral, N (%)**	**Chi-Square test for Independence**
SDM total				
Documented	29 (22.0)	59 (44.7)	44 (33.3)	X^2 (2, N = 211) = 5.48, p = .06, Φ = .16
Not documented	29 (36.7)	30 (38.0)	20 (25.3)	
Team talk				
Documented	28 (35.4)	31 (38.3)	20 (25.3)	X^2 (2, N = 211) = 5.48, p = .05, Φ = .17
Not documented	30 (37.0)	31 (38.3)	20 (24.7)	
Option talk				
Documented	2 (22.2)	4 (44.4)	3 (33.3)	-
Not documented	56 (27.7)	85 (42.1)	61 (30.2)	
Decision talk				
Documented	3 (11.1)	8 (10.8)	16 (59.2)	X^2 (2, N = 211) = 12.72, p = <.002, Φ = .25
Not documented	55 (29.9)	81 (44.0)	48 (26.1)	

Note. Chi-square statistics for option talk were not calculated because assumptions were not met.

in this regard which makes EPR documentation more likely. Patients with SDM documentation had fewer comorbidities than patients without SDM documentation. Moreover, patients with SDM documentation had more consultations than patients without SDM documentation. These findings seem to be in line with current literature [30,46]. However, as the subgroups for the separate SDM elements were relatively small and effect sizes were small, these results should be interpreted with caution. Option and decision talk were far less documented. This could be attributed to previous research indicating that GPs waver in deciding for which patient referral for specialized diagnostic testing is needed [47]. The decision on referral might therefore be viewed as a more explicit decision for which elaboration of options and patients' considerations should be discussed compared to follow-up in primary care. In line with this, decision talk was more frequently documented in EPRs of referred patients compared to patients who remained in general practice. Most patients in our study (71%) continued their diagnostics and care for memory complaints within the primary care setting. For many of these patients, the question on referral might not have come up or was not relevant, which might explain the little documentation of option and decision talk. Related to this, the fact that we identified patients with memory complaints in which dementia diagnosis was not a conversation topic, also contributes to this notion that a timely diagnosis may mean 'not ever officially' for some patients. As this patient group in our study was on average older than the group in which diagnostic strategies were discussed or applied, this may be the same relatively old patient group as those in which GPs indicate to be in little need of referral [47]. GPs also indicate difficulties in addressing dementia in patients with limited awareness of their cognitive problems [48]. Dementia diagnosis may therefore not be documented as a conversation topic because patients, significant others, and GPs implicitly agree on the lack of necessity for (specialized) diagnostic testing in these patients.

4.2. Strengths and limitations

Strengths and limitations in this study can be considered in the context of two main aspects. First, we used routinely collected primary care data from the FaMe registration network. Our study design presumes that GPs' SDM behaviour is reflected in their documentation, which is reasonable given the links between clinical reasoning, and its' documentation in EPRs [49]. GPs valuing SDM may use documentation to remind themselves of previous discussions with patients. However, time constraints or lack of prompts to document SDM in the EPR are barriers to extensive documentation of SDM [28]. GPs in the FaMe network are repetitively trained in registering medical data properly and extensively [31]. The SDM documentation in this study is likely to more closely reflect daily SDM practices than EPR documentation in other Dutch GP practices. Moreover, data collected in a natural context without prompts or observations provides an unbiased picture of SDM in daily general practice compared to other SDM studies. However, as documentation is dependent on which information GP write down, patients' perspectives on SDM are lacking in this approach, which is important as healthcare providers and patients can have different perspectives on their involvement in the SDM process [29,50].

Second, we explored the association between SDM documentation and a few patient characteristics that are known to be relevant for the use of the SDM such as comorbidity, polypharmacy, and age [30]. Nevertheless, we were not able to study the association with other potentially relevant factors. With regard to patients, the level of cognitive impairment is obviously a relevant factor for the application of SDM on which we lacked data. In the context of diagnostic testing for dementia, significant others have a prominent role in decision-making [51] as they are often the first ones to recognize early signs of dementia [52]. Their characteristics such as age, relationship with the patient with memory complaints, health status, and communication skills could be subject to future study [53].

4.3. Conclusion

Patient's and significant others' needs, goals, and wishes are often documented in EPRs when deciding on diagnostic testing for dementia in general practice, reflecting GPs' aim for a person-centered approach. Our findings highlight the role of healthcare professionals' perspectives on the importance of patients' context and goals for the decision at stake, contrary to limited person-centered focus found in EPR documentation previously. There were however only a few EPRs documenting explanations of the patients' options or the patients' involvement and considerations in decision-making, which illustrates the need for future SDM interventions to encourage patients, significant others, and GPs to actively engage in discussing options and determine which options best aligns with a patients' values.

4.4. Practice implications

Assessing current SDM in daily practice is essential for incorporating it into care. Documentation of SDM in EPRs may importantly reflect SDM and therefore be an important source to assess SDM approaches in clinical practice. At same time, it provides opportunities for professional feedback and support in undertaking SDM. This study's results showing mainly documentation of patients' considerations and goals (team talk) provide a window of opportunity to build further upon when designing interventions to support healthcare professionals in SDM in diagnostic testing for dementia. The documentation of patients' goals and wishes provides an opening for reflection on attitudes towards (the relevance of SDM) and gaps in SDM knowledge and skills. Moreover, the lack of option and decision talk documentation highlights the need for awareness on explaining options and achieving informed preferences. The

explanation of options or the use of patient decision aids could be prompted by EPRs [54], which could encourage the discussion of options and informed preferences by patients, significant others, and GPs. This could facilitate more timely dementia diagnoses and help GPs in achieving their ambition to diagnose patients at 'the right time' [12].

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CRediT authorship contribution statement

Iris Linden: Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Marieke Perry:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization. **Claire Wolfs:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization. **Henk Schers:** Writing – review & editing, Data curation. **Carmen Dirksen:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Rudolf Ponds:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Ethics approval statement

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

Appendix A

Data extraction

For each consultation on memory complaints a data extraction form was completed. Free text in the electronic patient file on which the answer in the data extraction form was based, was also extracted. The data extraction form was designed to capture the course of the consultation. It was developed through a group discussion with IL, CW, MP, CD and RP. Subsequently, the data extraction form was tested for 20 cases by IL and FF, afterwards the form was modified to issues that arose from these cases by IL, FF and MP. The variables comorbidity and chronic polypharmacy were extracted by the FaMe data extraction team and were not part of the data extraction form.

Question	Answer categories	
What was the RFE?	Worries patient	
	Worries significant other	
	Worries patient and significant other	
	Worries HCP	
	Follow up previous encounter	
	Unclear	
	Other, namely.	
What anamnestic information was noted down by the GP?	[Free text]	
MMSE score*	[number]	
Was hetero anamnesis performed?	Yes	
	No	
Did the patient (or significant other) express any expectations from the encounter?	Yes	
	No	
Did the patient (or significant other) express anxiety for developing dementia during the encounter?	Yes	
	No	
What decision is made concerning starting a diagnostic trajectory?	No clear decision was made	
	To wait and see	
	Diagnostic tests in general practice	MMSE
		Blood tests
		MOCA
		Other, namely
	Referral* *	
	Diagnosis is made during encounter	
	Other, namely.	

Note. *Only in case performed during encounter * *In case of a referral, this data extraction form was also completed for the referral letter from the GP, the outcome of the referral was also extracted.

Appendix B

	Total (n = 211)	Practice 1 (n = 87, 41.2%)	Practice 2 (n = 57, 27.0%)	Practice 3 (n = 67, 31.8%)	p-value
Age, mean (SD)	77.6 (8.45)	76.9 (8.3)	79.7 (9.4)	76.7 (7.6)	0.80
Female, n (%)	116 (55.0)	53 (60.9)	33 (57.9)	30 (44.8)	0.12
Comorbidity, mean (SD)	1.2 (1.5)	0.99 (1.2)	0.96 (1.2)	1.7 (2.1)	0.04
Polypharmacy, n (%)	50 (23.7)	22 (25.3%)	9 (15.8)	19 (28.4)	0.24
Number of consultations, mean (SD)	2.0 (1.1)	2.0 (1.2)	2.1 (0.9)	2.0 (1.0)	0.35

Note. To detect differences between general practices, one-way analysis of variance were performed for continuous variables or Kruskal-Wallis rank tests when the assumptions for one-way analysis of variance were not met. Chi-square tests were performed for categorical or dichotomous variables

Appendix C

	Total (n = 211)	Practice 1 (n = 87, 41.2%)	Practice 2 (n = 57, 27.0%)	Practice 3 (n = 67, 31.8%)	p-value
Team talk (n, %)	130 (61.6)	55 (63.2)	40 (70.2)	35 (52.2)	0.11
Option talk (n, %)	9 (4.3)	1 (1.1)	4 (7.0)	4 (6.0)	0.17
Decision talk (n, %)	27 (12.8)	9 (10.3)	9 (15.8)	9 (13.4)	0.62
SDM total (n, %)	132 (62.6)	56 (64.4)	41 (71.9)	35 (52.2)	0.07

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