Title: Patient and companion shared decision making and satisfaction with decisions about starting cholinesterase medication at dementia diagnosis

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Abstract

Background: There is little research on how people with dementia are involved in treatment decisions at diagnosis.

Objective: To measure shared decision making when starting cholinesterase inhibitors, investigate associations with contextual factors and explore satisfaction and experience of the diagnostic meeting.

Setting: Nine UK memory clinics in two geographical locations.

Subjects: 74 people receiving dementia diagnoses (with 69 companions) and 21 doctors.

Methods: We video-recorded 74 memory clinic consultations and rated doctor shared decision making behaviours using the Observing Patient Involvement in Decision Making scale (OPTION-5 scale). Patients and companions rated their satisfaction and experience. Mixed-effects regressions investigated involvement and (1) number people present, meeting length, capacity, cognitive functioning, diagnosis; and (2) patient/companion satisfaction and consultation experience.

Results: Mean consultation time was 26.7 minutes. Mean OPTION-5 score was 22.5/100 (Standard Deviation =17.3). Doctors involved patients in decisions more often when patients had mixed dementia (β=10.13, 95% confidence interval 1.25 to

19.0, *p=.025*) and in shorter meetings (β= -0.51, 95% CI -0.87 to -0.15, *p=.006*). Patient and companion satisfaction were high and not associated with whether doctors invited patient involvement. Half of patients and one-third companions were uncertain about the meeting outcome, experienced communication barriers and negative emotions.

Conclusions: Consultations scored low on shared decision making, but were comparable to other settings and were not lower with more cognitively impaired patients. Negative patient and companion experiences reflect the importance of supporting health care providers to address patient and companion emotions and need for information.

Background

How clinicians approach treatment discussions at dementia diagnosis can empower people to be involved in healthcare planning [1-3]. Shared decision making involves two-way information exchange between patient and clinician to arrive at a consensus about treatment [4]. It can increase satisfaction, treatment adherence and improve clinical outcomes [5,6]. There are challenges to shared decision making that may be further complicated with cognitive impairment [7]. However, lack of capacity due to dementia should not be assumed [8,9]. Patients with dementia wish to be involved in healthcare decisions [10] and express consistent preferences to be involved even with moderate cognitive impairment [11].

Medication decisions are often made when patients are informed that they have dementia, providing a window through which to observe how involved people with dementia are in decision making. There are few studies examining how decisions are made about whether to start cholinesterase inhibitors [12,13]. In this study, we used the Observing Patient Involvement in Decision Making scale [14], a widely used shared decision making coding scheme that has not been used with dementia diagnosis consultations. Using a standardised scale allowed us to explore associations with contextual factors and make comparisons with other settings.

Methods

Study design and setting

ShareD was an NIHR funded observational study collecting data from memory clinic diagnostic feedback meetings in two UK geographical locations (Study ID: PB-PG-1111-26063). Recruitment ran from May 2014 to April 2017. Camden and Islington Research Ethics Committee provided ethical approval (13/LO/1309).

Participants and recruitment

All doctors delivering diagnoses of dementia were eligible. The exclusion criteria for patients were age <65 and the need for an interpreter.

Doctors were contacted by the study team and those interested in participating provided written informed consent. Patients scheduled for a diagnostic feedback were informed of the study with their appointment letters and informed consent was obtained at clinic. Doctors assessed patient capacity to provide informed consent. Where patients lacked capacity Department of Health Guidance on nominating a consultee was followed [15].

Data collection

Diagnosis meetings were video-recorded. The researcher was not present. The number of people present and meeting length (in minutes) were confirmed using the recordings. The following measures were used:

Doctor involvement of patients in decision making

Video recordings were observer-rated by two trained researchers using the OPTION-5 [14]. This is the updated version of the OPTION-12, which the OPTION authors provided permission to use prior to its publication. The OPTION-5 consists of five items rating whether the doctor (1) describes different treatment options; (2) supports the patient in becoming informed; (3) checks understanding of all reasonable options; (4) supports patients to examine preferences; and (5) integrates patient preferences into the decision. Each item is rated from 0 ("no effort"), 1 ("minimal effort"), 2 ("moderate effort"), 3 ("good effort") to 4 ("exemplary effort") generating a total score of 0-20, rescaled to 0-100. The OPTION-5 is a valid and reliable measure of shared decision-making [16]. The researchers doing the rating were blinded to the other outcome measures. 22% of the videos (n=16) were rated by both researchers to test inter-rater reliability.

Cognitive Test Scores

Doctors administered the Mini Mental State Exam [17] or Addenbrooke's Cognitive Examination III [18] as part of their routine assessment.

Diagnosis and Capacity

Doctors recorded patient diagnosis and capacity to make treatment decisions. Capacity was indicated as 'none' or 'full'.

Patient Autonomy

Patients and companions completed the decision-making subscale of the Autonomy Preference Index [19] to evaluate patient preference for participation in decisions. The scale consists of six statements rated on from 1 "Strongly disagree" to 5 "Strongly agree".

Patient and Companion Satisfaction

Patients and companions filled out the Satisfaction with Decision scale [20], which measures satisfaction with health care decisions and consists of six items rated from 1 "Strongly disagree" to 5 "Strongly agree". The possible scores range from 6 to 30.

Patient and Companion Experience

The Patient Experience Questionnaire [21] is an 18-item questionnaire consisting of five subscales: (1) Outcomes of consultation (2) Communication with the doctor (3)

Emotions (4) Barriers to communication and (5) Auxiliary experience. The subscales are rated on a 5-point Likert scale except for the Emotion subscale rated on a 7-point scale. In the present study the Emotion scale comprised only three items (i.e. Sad-cheerful; Worn-out - strengthened; Worried - relieved), so the total PEQ score ranges from 17 to 91.

Data Analysis

The target sample size was 75 patients and 15 clinicians. This was calculated based on 3 predictors in a multiple regression analysis, ensuring the study was powered to detect a medium effect size (f2=0.15/ r=0.36) on the strength of the relationships between the predictors and involvement in shared decision making with 80% power, p=0.05.

Due to low frequencies (see Table 1), number of people present was recoded as a binary variable (Number of people present ≤3 or >3) and only Alzheimer's disease and Mixed dementia were included in the analysis.

Descriptive statistics were explored. Cronbach's alpha was calculated for questionnaires to determine internal consistency. Sum PEQ scores were calculated by summing individual items and dividing by the number of items within each scale. Histograms were produced to assist interpretation [21], scores below the subscale's midpoint were interpreted as indicating concerns.

To examine whether number of people, meeting length, patient decision-making capacity, cognitive functioning, and diagnosis were associated with OPTION-5 score, a linear mixed-effects regression model accounting for clustering on the doctor level (i.e. random effect) was estimated for each independent variable with OPTION as the dependent variable. Next, statistically significant variables at p<0.1 were entered into a multiple regression mixed-effects model with OPTION-5 score as the dependent variable.

To examine whether OPTION-5 score was associated with satisfaction and experience, two linear mixed-effects regression models were estimated with OPTION score as the independent variable and patient and companion satisfaction and experience as the dependent variables.

Results

Participants

Participant sociodemographic information can be found in Table 1. Participant flow is described in Figure 1. 215 patients were recruited (consent rate 51%). 101 people were diagnosed with dementia and in 75 meetings there was a decision about starting cholinesterase inhibitors. One patient was excluded as they were aged under 65, resulting in a sample of 74 patients and 69 companions. Most participants were diagnosed with Alzheimer's disease (70%), followed by Mixed dementia (19%). A Mixed dementia diagnosis indicates that features of Alzheimer's disease and Vascular dementia are present (coded in ICD-10 as Alzheimer's disease, atypical or mixed type (F00.2)).

Table 1: Participant characteristics.

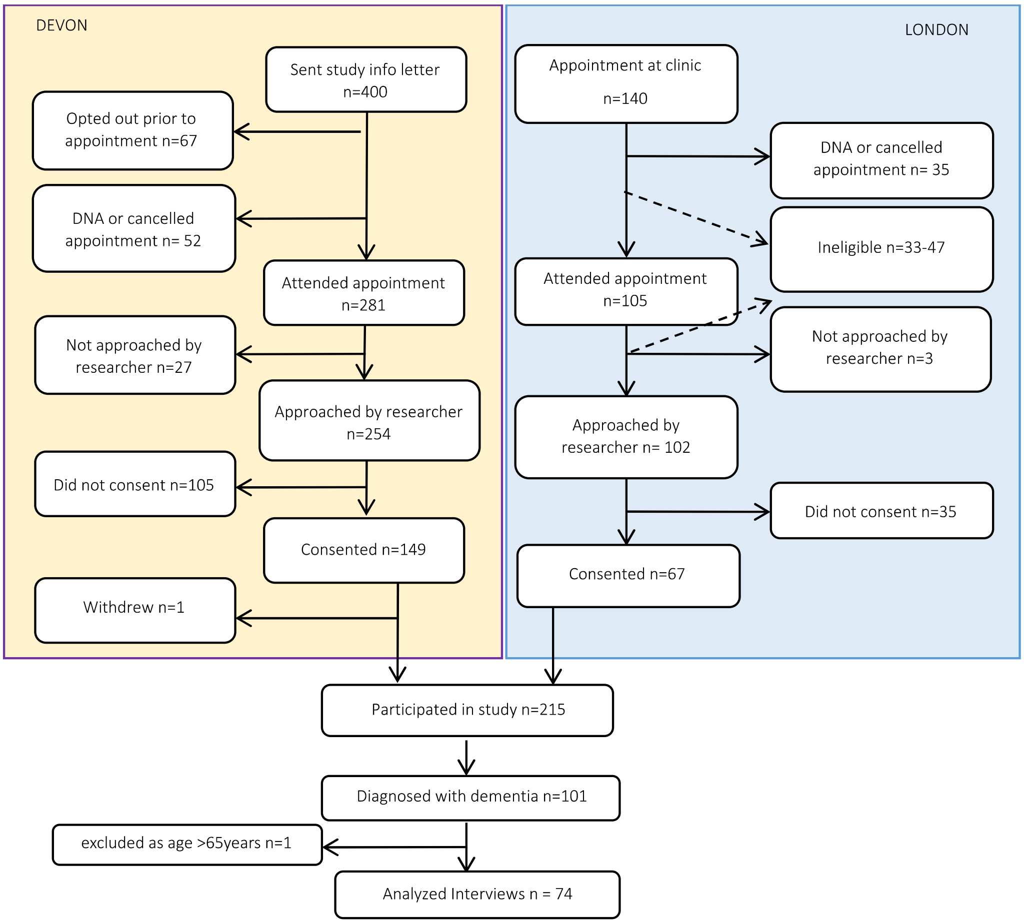
Characteristic		**Patients (n=74)** N (%) or *mean (SD)*	**Companions (n=69)** N (%) or *mean (SD)*
Site			
	London	31 (42%)	26 (37.7%)
	Devon	43 (58%)	43 (62.3%)
Gender			
	Male	29 (39%)	30 (57%)

Female	45 (61%)	39 (43%)
Age		
	81.7 (6.3) Range 65 to 91	63.6 (15.8) Range 26 to 90
Marital status		(n=68)
Single	2 (3%)	12 (18%)
Married/Partnership	41 (55%)	49 (72%)
Separated	2 (3%)	--
Divorced	11 (15%)	4 (6%)
Widowed	18 (24%)	3 (4%)
Ethnicity	(n=72)	(n=68)
White British	58 (80%)	57 (84%)
White Irish	3 (4%)	1 (2%)
White Other	3 (4%)	2 (3%)
Asian or Asian British	--	1 (2%)
Black or Black British	1 (2%)	2 (3%)
Caribbean	3 (4%)	3 (4%)
African	1 (2%)	--
Black other	--	1 (2%)
Any Other	3 (4%)	1 (2%)
Education level	(n=71)	(n=68)
School (GCSE)	43 (61%)	27 (40%)
Further Education (A-level)	15 (21%)	19 (28%)
Higher Education (beyond A-level)	13 (18%)	22 (32%)
Diagnoses received		
Alzheimer's dementia	52 (70%)	
Mixed dementia	14 (19%)	
Parkinson's disease dementia	2 (3%)	
Unspecified dementia	4 (5%)	
Lewy body dementia	2 (3%)	
Capacity		
None	20 (27%)	
Full	44 (60%)	
Missing	10 (13%)	

Companions were spouses/partners (n=30, 40%), children/children in law (n=27, 36%), siblings (n=2) and friends (n=2). Eight 8 identified as ‘other’. Five patients (7%) were not accompanied.

Twenty-one doctors participated in the study (consent rate 88%). They were consultant psychiatrists (n=15) or geriatricians (n=3), psychiatry registrars (n=2) and one speciality doctor in psychiatry. In 49 (66%) consultations there was just the doctor present. In 24 (32%) there was an additional clinician and in one there were two additional clinicians. These were social workers (n=9) dementia support workers (n=6), nurses (n=4), registrars (n=4) and medical students (n=3).

Figure 1. Study recruitment flow chart.



Measures

Mean consultation time was 26.7 minutes. Descriptive findings for each measure are presented in Table 2.

Table 2: Statistics for study variables and Mixed multiple regression mixed effect model.

Measure	**N**	**% or mean *(SD)***	**Range**
OPTION score (rescaled to 1-100)	74	*22.50 (17.25)*	0 to 90
Item 1 '*Presenting multiple options'*	74	*0.86 (0.88)*	0 to 3
Item 2 *'Establishing partnership'*	74	*0.34 (0.69)*	0 to 4
Item 3 '*Check understanding of all options'*	74	*1.32 (0.86)*	0 to 4
Item 4 '*Examine preferences'*	74	*1.04 (1.05)*	0 to 4
Item 5 '*Integrating preferences'*	74	*0.93 (1.00)*	0 to 4
Number of people present in meeting* (n=74)			
2 people	1	1.35%	
3 people	46	62.16%	
4 people	22	29.73%	
5 people	3	4.05%	
6 people	2	2.70%	
Meeting length	74	27m 40s (9m 36s)	7m 25s to 54m 22s
Patient capacity (n=64)			
None	3	4.69%	
Partial	17	26.56%	
Full	44	68.75%	
Cognitive test score (n=70)			
ACE-III (out of 100)	61	68.39 (11.57)	41 to 94
MMSE (out of 30)	12	23.08 (4.64)	15 to 28
API (out of 100)	68	46.91 (12.37)	20 to 75
Patient **SWD** (out of 30)	56	24.45 (2.00)	17 to 29
Companion **SWD** (out of 30)	42	25.26 (3.04)	19 to 30
Patient **PEQ**			
Outcome (out of 5)	57	3.01 (0.86)	1.25 to 5
Communication (out of 5)	66	4.18 (0.54)	2.5 to 5
Barriers (out of 5)	68	3.13 (0.67)	1.5 to 4.25
Auxiliary (out of 5)	64	4.01 (0.75)	2 to 5
Emotions (out of 7)	67	4.09 (0.66)	3 to 5.67
Total (out of 27)	51	20.76 (2.43)	15.5 to 25.75
Companion **PEQ** (out of 91)			
Outcome (out of 5)	64	3.46 (0.80)	2 to 5
Communication (out of 5)	62	4.46 (0.49)	3.5 to 5
Barriers (out of 5)	62	3.56 (0.49)	2.25 to 4
Auxiliary staff (out of 5)	61	4.34 (0.73)	2.5 to 5
Emotion (out of 7)	60	4.78 (0.74)	3 to 6.67

	Total	57	23.03 (2.11)	18.25 to 26.5

Mixed Effects model	**Variable**	**Beta (β)**	**95% Confidence Interval**	**P-value**
	Meeting length	-0.51	-0.87 to -0.15	*.006*
	Diagnosis	10.13	1.25 to 19.00	*.025*
	Number of adults	-6.79	-14.32 to 0.73	*.077*

Internal Consistency

Internal consistency of scales was estimated using Cronbach’s alpha. OPTION-5 Cronbach’s alpha was .82. The remaining Cronbach’s alpha scores were (for patients and companions respectively): .65 and .90 for the SWD scale; .62 and .71 for the PEQ Outcome subscale; .77 and .80 for the PEQ Barriers subscale; .67 and .72 for the PEQ Emotion subscale and .63 and .80 for the PEQ Communication subscale. Although internal consistency of patient rated scales was borderline acceptable, they were retained for analysis given the exploratory nature of this study.

The API and patient and companion PEQ Auxiliary subscales had poor internal consistency (alpha= .60, .58, and .53, respectively) and were not used in further analyses.

Doctor involvement of patients in decision making

Cohen’s weighted kappa demonstrated substantial agreement between OPTION-5 raters (κ=0.75). The mean OPTION-5 score was 22.50/100. Mean item scores (see Table 2) were highest for item 3 ‘describing the pros and cons and checking understanding’ (mean=1.32) and item 4 ‘examining patient preferences’ (1.04), lower for ‘integrating preferences’ (0.93), ‘presenting multiple options’ (0.86) and lowest for item 2 ‘supporting patients to be informed’ (0.34).

Satisfaction with Communication

Patient and companion scores on the SWD scale were mean 24.45 (SD 2.00) and 25.26 (SD 3.04) respectively. Over 90% of patient and companion ratings were at least 4 out of 5.

PEQ scores were more varied. 59.7% of patients and 35.9% of companions expressed uncertainty on the Outcome scale (i.e. mean scores at or below midpoint). 51.5% of patients and 26.8% of companions reported barriers to communication (Barriers scale). On the Emotion scale, 53% of patients and 21.7% of companions felt negative or no positive emotion. On the Communication scale, 4.6% of patients and no companions described communication as less than optimal.

Bivariate Associations

A significant association between the number of people present and OPTION-5 score was identified (β=8.56, 95% CI -16.55 to -0.57, *p=.03*), indicating that doctors invited less patient involvement when there were more than three people present.

There was a statistically significant inverse association between the length of the meeting in minutes and OPTION-5 score (β= -0.47, 95% CI -0.89 to -0.06, p=.02). This means that there was a 0.47-point decrease in involvement in decisions with each additional minute in length of the meeting

The mean OPTION-5 score in patients with None/Partial capacity to make treatment decisions was 25.5 (SD=18.63) and in those with Full capacity was 21.25

(SD=17.66). No significant association was identified (β=-4.25, 95% CI -13.93 to 5.43, *p=.31*).

There was no evidence that OPTION-5 score was associated with cognitive impairment on the MMSE (n=12; *p=.33*) or ACE-III (n=61; *p=.78*).

The mean OPTION-5 score was 31.4 (SD=22.8) and 19.7 (SD=14.2) for patients with Mixed dementia and Alzheimer's disease, respectively. This was a statistically significant association (β=9.39, 95%CI 0.05 to 18.72, *p=.05*).

We observed no significant association between OPTION-5 score and patient or companion satisfaction with the decision (SWD, *p=0.34* and *p=0.71* respectively), or subscale and total experience scores (PEQ, patients all p values≥0.49, companions all p values≥0.58).

Multiple regression mixed-effects model

Significant predictors on a bivariate level (meeting length, diagnosis received and number present) were entered into a multiple regression model with the doctor included as a random effect and OPTION-5 as the dependent variable (Table 2). Doctors involved patients in decisions more often when patients had mixed dementia (β=10.13, 95% confidence interval 1.25 to 19.0, *p=.025*) and in shorter meetings (β= -0.51, 95% CI -0.87 to -0.15, *p=.006*).

Discussion

Shared decision making scores about dementia medication were low, with a mean of 22.5/100 on the OPTION scale [22]. Involvement was higher when patients had Mixed dementia diagnoses rather than Alzheimer's disease, and in shorter meetings. Cognitive impairment and capacity were not observed to impact shared decision making. Satisfaction was high, but half of patients and one third of companions reported negative experiences.

While shared decision making scores were low, they were similar to other settings. A systematic review of OPTION-12 found only 38% of studies have average scores over 25/100 and almost all are under 50 [23]. Hence, low involvement appears not to be due to dementia. Alongside the fact that capacity and cognitive test scores did not impact on scores, this demonstrates doctor willingness to include people with dementia in decisions. However, it does suggest there is room for increasing patient involvement in decision making across all medical settings.

It is important to reflect on the OPTION tool as a measure of shared decision making. We observed no significant association between OPTION scores and satisfaction or experience. A 2015 review found that in the 6 studies linking observer rated measures of shared decision making with outcomes, only two found associations, with one showing improved satisfaction with higher OPTION scores [24]. Our concept of shared decision making is intricately linked to how it is measured. A study by this team using a more fine-grained approach to analysis found lower satisfaction scores when doctors recommended treatment in a more directive way (i.e. "I will prescribe a medication" versus "would you like to try a medication") [25]. This highlights the methodological challenges of assessing shared decision making [26], specifically the level of detail that is captured in how doctors communicate.

Patient experience of the diagnosis meeting was somewhat negative, in line with other studies of dementia diagnosis [27]. This diagnostic context may explain why doctors scored lower on integrating patient preferences for not taking medication, doctors wish to offer hope at diagnoses and medication has this symbolic value [28]. Doctors are concerned about overwhelming patients [13]. However, patient well-being is affected by the perceived quality of disclosure [29]. Half of patients and one third of companions had limited understanding of dementia and experienced barriers in communication. Hence, it may be that doctors need support to balance understanding and hope in delivering dementia diagnoses [30,31].

While previous studies have found more involvement in longer meetings [23], or no association [6], we found less involvement in longer meetings. Longer meetings may reflect other factors, e.g. increased complexity due to diagnostic uncertainty leaving less time for decision-making. Patients diagnosed with Mixed dementia were more involved in decision-making compared with Alzheimer's disease alone. Identifying the patient, companion and clinician factors underlying this should be explored in future research.

The findings should be considered in the light of the study's strengths and limitations. Strengths include the first empirical analysis of decision-making in dementia, using the validated OPTION scale, observer-rated using video recordings. We captured multiple facets of patient and companion perception to reduce methodological challenges of satisfaction research. However, we could not include the API in the analysis due to poor internal consistency, which has also been the case in other patient populations [32]. The study was powered to detect medium relationships between variables (r=.35), and the internal consistency of some of the included scales were modest. Categorial variables (patient capacity, number of people present, diagnosis) are less sensitive than continuous variables, impacting on the likelihood of detecting associations. Finally, some self-report scales may be rendered invalid when MMSE scores are below 20 [32]. While most patients were tested using the ACE-III, three patients scored <20 on the MMSE.

To conclude, while OPTION-5 scores were low, they were comparable to other settings and were not lower with more cognitively impaired patients. Nonetheless, there is scope for increasing involvement of people with dementia in decisions. Healthcare providers should be aware that although they elicit patient preferences, these are not always incorporated into the final decision. Half of patients and one third of companions reported negative experiences of receiving a diagnosis of dementia. Supporting healthcare providers in communication may address an unmet need for emotional support and adequate information at diagnosis.

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