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Title: How doctors involve patients with dementia in decisions to initiate treatment: Effect on patient acceptance, satisfaction, and medication prescription.

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Abstract

Background: Shared decision making is advocated, but may be affected by cognitive impairment. Measures of shared decision making provide global descriptions of communication without detailed analysis of the subtle ways in which doctors invite patient input.

Aims: To explore medication decisions in dementia using a standardised Treatment Recommendation Coding Scheme.

Methods: 71 video recorded dementia diagnostic meetings from 9 memory clinics were coded. Doctors recommended treatment using 5 different formats: pronouncements (“I will start you on medication”), proposals (“shall we try medication?”), suggestions (“would you like to try medication?”), offers (“I can prescribe medication”), and assertions (“there is medication”). Patient responses were coded as acceptance (“I’d like to have that”), active resistance (“I’m not very keen”), and passive resistance (minimal or no response). Cognitive test scores, prescription rates, and satisfaction were assessed and associations explored.

Results: Doctors used suggestions in 42% of meetings, proposals in 25%, assertions in 13%, pronouncements in 11%, and offers in 9%. Over 80% of patients did not indicate clear acceptance. Patients were most likely to actively resist after suggestions. There was no association between cognitive impairment and recommendation format. Patients were less satisfied with pronouncements. Patient preference did not influence whether medication was prescribed.

Conclusions: Doctors in memory clinics initially nominate patients as the decision maker, and this is not affected by cognitive impairment. Although over 80% of patients resisted the option of starting medication, medication still tended to be prescribed, indicating factors other than patient preference affect prescription.

Declarations of Interest: None

Introduction

Involving patients in decisions about their psychiatric treatment has been shown to increase patient satisfaction, treatment adherence and improve clinical outcomes (1). There has been little research observing how doctors communicate with people with dementia when making decisions about anti-dementia medication (2), but there is an indication that shared decision making may be low (3). **The inherent cognitive impairment of dementia, alongside the increasing role of family, has been shown to impact on patient involvement (4).**

However, people with dementia, like other illnesses, want to be involved in discussions about their care (5).

Most research on shared decision making has used scales which offer a global picture of patient involvement, such as whether doctors ask patient preferences or list options (6, 7). However, analysis of *how*, rather than *whether*, doctors discuss medication with patients is vital for a more nuanced understanding. How doctors recommend treatment is particularly vital: it is at this point that the patient is identified either as the primary decision maker or a passive party (8). Recently, a novel approach examining how doctors format treatment recommendations in more or less authoritative ways has been developed (9). As Stivers and colleagues point out, there are clear differences between “I’m going to start you on X”, “We can give you X to try” and “Would you like me to give you X”. As these different formats are more or less authoritative, they afford patients different degrees of autonomy to decide whether or not to accept or resist treatment recommendations. Furthermore, just as medication recommendations are subtly different, subtle differences in patient responses indicate either acceptance or resistance. A well-established body of studies on agreement and disagreement in interaction have shown that acceptance occurs quickly and positively, and resistance can be passive or active (10-12). Passive resistance involves a delayed response, withheld response, or a minimal verbal (e.g. mhm) or non-verbal response (a nod), while active resistance involves explicit statements of non-agreement or questioning the recommendation (10).

The aim of this study was to analyse how doctors involve patients with cognitive impairment in decisions to start medication, and whether this has an effect on patient acceptance of

medication. Associations with patient cognitive functioning, satisfaction, and prescription were also explored.

Materials and Methods

Camden and Islington National Research Ethics Committee approved the project (13/LO/1309). The data was collected as part of the NIHR RfPB funded Shared decision making in mild to moderate Dementia study (ShareD - PB-PG-1111-26063). This was an observational study collecting video recordings from routine memory clinic diagnostic feedback appointments where patients were told whether or not they had dementia. Recruitment was conducted in two sites in the UK – London (urban) and Devon (rural). In London, there were six participating memory clinics across three NHS trusts. In Devon, there were three participating memory clinics within one NHS trust. Recruitment ran from May 2014 to July 2016.

Recruitment

We approached all clinicians delivering dementia diagnoses in the participating trusts. The aim was to recruit all consecutive patients attending the memory clinic for diagnosis feedback, except for those needing interpreters due to the added complexity of the communication. Administrative staff sent information sheets with patient appointment letters. Clinicians assessed whether patients had capacity to provide informed consent, and researchers approached patients and their companions to discuss the study. Two patients in this study were judged not to have capacity, and in these cases we followed the Department of Health guidance on nominating a consultee for research involving adults who lack capacity to consent (13) .

Data Collection

Treatment Recommendations and Responses

We filmed patients' meetings with their clinician using GoPro cameras without the researcher present. The meetings were transcribed verbatim and medication discussions identified. Detailed, conversation analytic transcription methods were used for the excerpts of the meeting containing treatment recommendations and responses to illustrate

characteristics of speech such as pauses, overlap, stress, intonation, and pace (14). For clarity, these symbols have been removed where extracts and quotes have been presented in this paper but are available from the authors on request.

Patient capacity

Patient capacity to make decisions about medication was recorded by clinicians after the meeting. Capacity was recorded as full, partial or no capacity.

Cognitive test score

Cognitive functioning was assessed by clinicians using the ACE-III (15) or MMSE cognitive test (16) as part of usual practice.

Patient satisfaction

After the meeting the patient completed the Patient Experience Questionnaire (PEQ) (17). The communication subscale of the PEQ was used to obtain communication-specific satisfaction ratings. This subscale contains 4 statements (“we had a good talk”; “I felt reassured”; “the doctor understood what was on my mind” and “I felt I was taken care of”) each with a 5 point Likert scale from “Agree completely” to “Disagree completely”. The total possible score is 20.

Prescription outcome

Whether medication was prescribed or not was identified from the recordings. The reason for not prescribing medication was recorded.

Data Analysis

Treatment recommendation

Each recommendation was coded using the “Treatment Recommendation Coding Scheme” (9), which was developed in US and UK primary care, and in UK psychiatry and neurology settings. The coding scheme was comprehensively developed using conversation analytic methods that examined inductively how treatment recommendations are made in practice.

The coding scheme includes 5 recommendation formats as follows:

1. Pronouncements – patients are given no choice, e.g. “I will start you on medication”
2. Proposals – patients are invited to endorse or collaborate with the doctor’s idea, e.g. “How about trying medication?”
3. Suggestions – medication is endorsed by doctors but patients are given the choice, e.g. “Would you like to try medication?”
4. Offers – doctors show a willingness to prescribe for the patient, but do not actively endorse medication, e.g. “Do you want me to give you medication?”
5. Assertions – doctors state the fact that medication exists without endorsement or explicit recommendation, e.g. “There is a medication”.

Patient Responses

Using the coding scheme, the patient response was coded as:

1. Acceptance – quick positive acceptance, e.g. “I’d like to have that”.
2. Passive resistance – minimal verbal or non-verbal acknowledgment, e.g. “mhm” or nodding, or no response.
3. Active resistance – questioning the purpose of medication or indicating a wish not to take the medication, e.g. “I’m not very keen, I don’t want to take more tablets”.

Two researchers coded all the recommendation formats and patient responses and discrepancies were resolved through discussion.

Relationships between treatment recommendation, patient acceptance or resistance, and whether medication was prescribed were explored using Fischer’s exact tests. Possible associations between recommendation format and patient acceptance or resistance, cognitive test score, and patient satisfaction were explored using ANOVA. The authors were not blinded to these factors when conducting the coding and analysis.

Results

The consent rate for clinicians in the study was 88%. Of the 215 patient participants (consent rate 51%), 101 were diagnosed with dementia. Of the 101 video recorded meetings where patients received a diagnosis of dementia, 71 were included (Figure 1). In

the remaining 30 recordings there were 6 cases of equipment malfunction, 18 vascular dementia diagnoses where medication was not offered, and 1 semantic dementia diagnosis where medication was not offered. In 5 Alzheimer's disease cases medication was not recommended: either medication was not discussed at all, or it was discussed but not presented as an option.

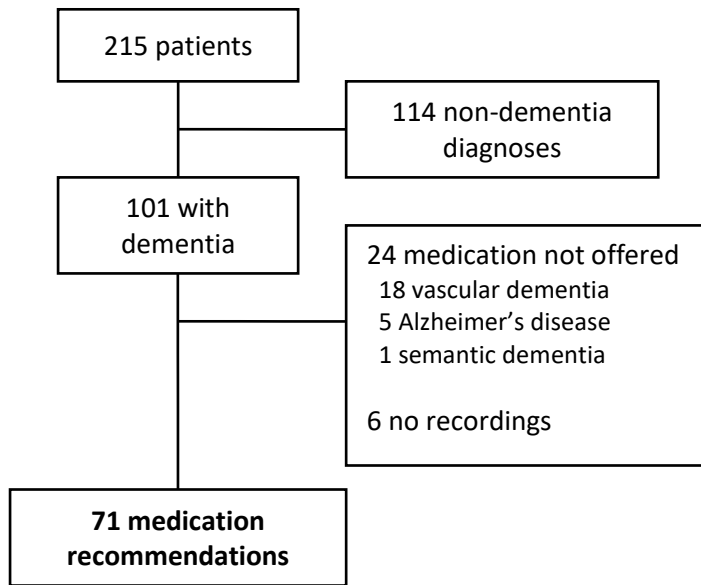


Figure 1: Patient flow diagram

Participant Characteristics

Participant characteristics are displayed in Table 1. There were 71 patients, 67 companions, and 21 doctors. Most patients were white, receiving a diagnosis of Alzheimer's disease or mixed dementia. Nearly two thirds were female. Where doctor judgement of patient capacity to make medication decisions was recorded, 70% had full and 22% partial capacity. Companions were present in most meetings and were nearly always spouses/partners or children/children in law. Doctors were primarily psychiatrists, with 3 geriatricians.

Table 1: Participant Characteristics

Site (n, %)	
London	30 (42%)
Devon	41 (58%)
Patient sex (n, %)	
Female	44 (62%)
Patient Age (mean, range)	81 (65-91)
Patient Ethnicity (n, %)	
White British/Irish	59 (82%)
White Other	3 (4%)
Caribbean	3 (4%)
Black or Black British	1 (2%)
African	1 (2%)
Other	2 (3%)
Missing	2 (3%)
Patient Diagnosis (n, %)	
Alzheimer's disease	49 (69%)
Mixed dementia	14 (20%)
Dementia unspecified	4 (5%)
Parkinson's disease	2 (3%)
Lewy body dementia	2 (3%)
Patient Cognitive Test Score (mean, range)	
ACE-III (n=58)	69 (41-94)
MMSE (n=11)	23 (15-28)
Patient Capacity to make Decision about Medication (Judged by doctor) (n, %)	
Full	43 (61%)
Partial	16 (22%)
None	3 (4%)
Missing	9 (13%)

Companion Present (n, %)	67 (94%)
Companion Type (n, %)	
Spouse/partner	27 (40%)
Child/child in law	27 (40%)
Sibling	2 (3%)
Friend	2 (3%)
Other	8 (12%)
Missing	1 (2%)
Professional Type (n, %)	
Consultant Psychiatrist	15 (71%)
Consultant Geriatrician	3 (14%)
Specialty Doctor	3 (15%)
Professional number of years working in dementia (mean, range)	12 (1-25)
Professional Gender (n, %)	
Female	11 (52%)
Ethnicity (n, %)	
White British	14 (66%)
White Other	3 (14%)
Asian or Asian British	2 (10%)
Indian	2 (10%)

Treatment Recommendation Formats and Responses

Treatment Recommendation Formats

Doctors primarily formatted treatment recommendations in a way that nominated the patient as primary decision maker. In 73% of treatment discussions, doctors initiated the discussion with assertions, i.e. a general statement about the existence of medication such as “there are medications we can try”. These preliminary statements usually either contained a reference to the tablets not being a cure and/or a description of side effects. In the majority of meetings where discussions started with assertions, these assertions were treated as information giving: there was little response from patients and doctors quickly moved on to the treatment recommendation proper. Extract 1 is an example of this:

Extract 1:

1 DR: now (0.6) there is some medication (.) that (0.3) many
2 people take (.) to help with the symptoms of memory loss
3 (0.5)
4 DR: and about two thirds of people find it gives them some
5 benefit
6 (0.4)
7 DR: uhm some people most people don't but some people get some
8 side effects such as a little bit of nausea or a loose stool
9 or a headache or or a feeling of dizziness
10 (0.6)
11 DR: **would you like to think about taking some medication**
12 (0.6)
13 PT: yes well (0.9) see how it goes I've got a lot of
14 medication I take almost every day

The doctor asserts that there is “some medication” to help memory loss in lines 1-2, followed by the caveats that not all people will benefit (lines 4-5) and that “some people get some side effects” (lines 7-9). This is followed by a suggestion in line 11, where the doctor nominates the patient as the decision maker: “would you like to think about taking some medication”.

Suggestions, as in Extract 1, were used in 42% of meetings. Proposals were used in 25% meetings (“we could try you on a tablet to help contain or maintain or make this stable in the future”), pronouncements in 11% of meetings (“I would want you to start at least taking medication”) and offers in 9% meetings (“the other thing we can do is to give you a tablet if you would like”). Assertions were used as the only treatment recommendation type in 13% (“there is now medications that we can offer people”).

Patient Responses

Forty-five patients (63%) passively resisted medication by responding minimally (e.g. “mhm”), nodding, or not responding. 13 patients (18.5%) actively resisted medication (“is it going to help, I take medication already”), and 13 patients (18.5%) explicitly accepted medication (“yes I’ll take them”).

Association between recommendation format and patient response

There was a significant association between recommendation format and patient response (Fisher’s Exact Test: $p=0.014$). Patients only actively resisted medication after suggestions or proposals, and always passively resisted pronouncements (see Table 2). Just over half the time that patients accepted medication, doctors had used proposals.

Table 2: Treatment Recommendation, Response, and Prescription Outcomes

	Acceptance	Passive Resistance	Active Resistance	Total
Pronouncement	0	8	0	8
Proposal	7	9	2	18
Suggestion	3	16	11	30
Offer	1	5	0	6
Assertion	2	7	0	9
Total	13	45	13	71
Prescribed	9	36	9	54
Not Prescribed	4	9	4	17

Recommendation format and cognitive test score

There was no association between recommendation format and the patient's level of cognitive impairment as shown on the ACE-III ($F(4,53) = .478, p = .751$) or MMSE ($F(3,7) = .557, p = .660$).

Recommendation format and patient satisfaction

Patients were significantly less satisfied with the communication when they were not offered a choice in taking medication, i.e., when pronouncements were used (14.3/20) compared to other recommendation formats (16.5-17.3/20) ($F(4,59) = 3.047, p = .024$).

Patient response and prescription outcomes

Medication was prescribed in 76% (n=54) of the meetings. There was no association between patient acceptance or resistance and whether medication was prescribed (Fisher's Exact Test, $p=.561$). Medication was just as often prescribed when patients resisted as when they accepted (see Table 2).

In the 17 cases where medication was not prescribed, 9 (53%) decisions were deferred for further investigation, either an ECG or referral to neurology. In 4 cases (24%) patients expressed a wish to talk to family or their GP before making a decision, and in 2 cases (11.5%) there was a joint decision not to take medication. In the remaining 2 cases (11.5%) the doctor decided to defer the decision until support was in place from the community mental health team.

Discussion

Doctors in memory clinics overwhelmingly nominated patients as the decision maker when starting medication for dementia. Over 80% of patients appeared to show some reluctance to start medication, primarily through passive resistance. However, medication still tended to be prescribed.

The use of assertions to initiate medication discussions has also been described in neurology (18). Assertions are poised between informing the patient about medication and recommending medication to the patient. This places very little interactional pressure on the patient for an immediate decision, thus allowing for further discussion. Toerien describes assertions as 'cautious recommendations' in environments of diagnostic uncertainty, likely patient resistance, and uncertain efficacy of the medication (18). In memory clinics, patients will be dealing with a life-changing diagnosis of dementia. The use of assertions prior to an explicit recommendation may therefore facilitate a smoother, more sensitive transition between the diagnosis and decision making about treatment.

Doctors used fewer pronouncements than in primary care (65% US, 45% UK) (9) and general psychiatry (25%) (19). This suggests a higher willingness to include patients in medication decisions at dementia diagnosis. Indeed, two thirds of treatment recommendations were suggestions or proposals, demonstrating that doctors endorse medication as a treatment option but are encouraging patient participation in the decision. However, subtle differences in the precise formulation of the recommendation have an effect on patient response. With proposals, doctors are inviting patients to join in with their endorsement of medication. With suggestions, doctors are inviting the patient to decide whether they would like to start medication (9). This has important consequences for how patients respond: proposals led to higher levels of acceptance whereas suggestions led to higher levels of resistance. This demonstrates how subtly different formats create different possibilities for patient choice and participation in decision making.

The majority of patients appeared to show some reluctance to start medication. However, previous work on resistance to treatment recommendations has been done with cognitively intact patients in primary care and patients with psychosis in outpatient psychiatric care. It may be that passive resistance – a non-verbal response or a minimal verbal response – in cognitively intact patients does not indicate passive resistance in people who are cognitively impaired. For example, there is evidence that reaction times in conversation can be 5 times slower for people with moderate dementia than people without dementia (20). Therefore, people with dementia may be responding more slowly when withholding a response rather

than resisting. Conversely, people with dementia have also been found to agree more in conversation, suggesting an attempt to remain engaged in the interaction, through assent, rather than actual agreement (21).

Although marginalisation of people with dementia has been described in previous studies (2, 22, 23), doctors involved patients in decisions irrespective of cognitive impairment. This is a positive finding demonstrating that doctors in UK memory clinics are not excluding patients with lower cognitive test scores from decisions about their medication, and in line with patients' preferences to be involved in decision making (4, 5). However, the majority of patients in this study were in the mild to moderate stages of dementia and decision making with people in later stages may be different.

Patients were significantly less satisfied with communication when they are not offered a choice ("I'll start you on medication"), illustrating that patients detect subtle differences in communication. This is in line with other studies of shared decision making (24) and demonstrates the importance of including people with dementia in decisions. It must however be noted that patients were rating their satisfaction with communication in the meeting as a whole, and there could be other communication difficulties affecting patient experience and potentially causing doctors to use pronouncements when it came to recommending medication.

Patients' acceptance or resistance of medication did not influence whether medication was prescribed. In 69% of cases where patients actively resisted medication (9/13), it was nonetheless prescribed. If medication was not prescribed, this was usually due to a need for further investigation (ECG or neurology) or doctors planning to put other support in place first, further indicating the doctor's authority in the outcome of medication decisions.

However, there are other factors which are likely to come into play here. In this study, 8% of patients were judged not to have capacity to make medication decisions and 22% were judged to have partial capacity. Moreover, doctors report wishing to offer medication to instil hope after breaking bad diagnostic news, and therefore may find it difficult not to prescribe medication (25). Family preferences may also come into play: doctors have been shown to invite family involvement in medication discussions more than in other parts of

the consultation (26), and caregivers deem medication to be important for access to services and to provide hope for the future (27). However, it is worth noting that only the patient's initial response to the treatment recommendation was taken into account in this analysis, and it may be that they would have changed their minds after further discussion.

Strengths and Limitations

The strength of this study was the systematic, standardised analysis of treatment recommendations, using a novel approach to capture more subtle aspects of shared decision making. This is relevant both to old age psychiatry and other areas of psychiatry where patients may experience cognitive impairment such as schizophrenia or intellectual disabilities. This study is the first to use this detailed method to examine decision making when people receive a diagnosis of dementia, and includes a range of patients, doctors, and clinics. However, doctors knew they were being filmed and this may have affected their behaviour. The researchers who coded the transcripts and conducted the analysis were not blinded, which may add bias. Companion behaviour was not analysed, which may have impacted on decision making. Additionally, the majority of the patient were white, and consultations using an interpreter were not included, which limits generalisability.

Conclusions

Doctors included patients with cognitive impairment in decisions about starting medication after receiving a diagnosis of dementia. Most often, they nominated the patient as the primary decision maker. This allowed patients to resist, with over 80% appearing to show some reluctance towards starting medication. Medication still tended to be prescribed, suggesting factors such as patient capacity, doctors' wishing to offer hope and companion involvement are also important in decisions to start medication.

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References

1. McCabe R, Priebe S. The therapeutic relationship in the treatment of severe mental illness: a review of methods and findings. *International Journal of Social Psychiatry*. 2004;**50**(2):115-28.
2. Dooley J, Bailey C, McCabe R. Communication in healthcare interactions in dementia: A systematic review of observational studies. *International Psychogeriatrics*. 2015;**27**(8):1277-300.
3. McCabe R, Dooley J, Bass N, Russell A, Xanthopoulou P, Livingston G. Shared decision making in mild to moderate dementia. In preparation.
4. Miller L, Whitlatch, C, Lyons, K. Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*. 2016;**15**(5):1141-1157.
5. Hamann J, Bronner K, Margull J, Mendel R, Diehl-Schmid J, Bohner M, et al. Patient Participation in Medical and Social Decisions in Alzheimer's Disease. *Journal of the American Geriatrics Society*. 2011;**59**(11):2045-52.
6. Pellerin M, Elwyn G, Rousseau M, Stacey D, Robitaille H, Legare F. Toward shared decision making: using the OPTION scale to analyse resident-patient consultations in family medicine. *Acad Med*. 2011;**86**(8):1010-8.
7. McCabe R, Khanom H, Bailey P, Priebe S. Shared decision-making in ongoing outpatient psychiatric treatment. *Patient Education and Counseling*. 2013.
8. Elwyn G, Hutchings H, Edwards A, Rapport F, Wensing M, Cheung W, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision making tasks. *Health Expectations*. 2005;**8**:34-42.
9. Stivers T, Heritage J, Barnes R, McCabe R, Thompson L, Toerien M. Treatment Recommendation as Actions. *Health Communication*. 2017;**32**(9).
10. Stivers T. Parent resistance to physicians' treatment recommendations: One resource for initiating negotiation of the treatment decision. *Health Communication*. 2005;**181**(1):41-74.
11. Ijas-Kallio T, Ruusuvaori J, Perakyla A. Patient resistance towards diagnosis in primary care: Implications for concordance. *Health (London)*. 2010;**14**(5):505-22.
12. Heritage J, Selfi S. Dilemmas of advice: aspects of the delivery and reception of advice in interactions between health visitors and first time mothers. In: Drew P, Heritage J, editors. *Talk at Work: Interaction in Institutional Settings*. London: Cambridge University Press; 1992.

13. Health Do. Guidance on nominating a consultee for research involving adults who lack capacity to consent. 2005.
14. Jefferson G. Glossary of transcript symbols with an introduction. In: Lerner GH, editor. *Conversation Analysis: Studies from the first generation*. Amsterdam: John Benjamins; 2004.
15. Hodges J, inventor Addenbrooke's Cognitive Examination — III (ACE-III). Australia 2013.
16. Arevalo-Rodriguez I, Smailagic N, Ciapponi A, Sanchez-Perez E, Giannakou A, Roqué i Figuls M, et al. Mini-Mental State Examination (MMSE) for the detection of Alzheimer's disease and other dementias in people with mild cognitive impairment (MCI). *Cochrane Database of Systematic Reviews* [Internet]. 2013; (10). Available from: <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010783/abstract>.
17. Steine S, Finset A, Laerum E. A brief new questionnaire (PEQ) developed in primary healthcare for measuring patients' experience of interaction, emotion and consultation outcome. *Family Practice*. 2001;**18**:410-8.
18. Toerien M. Deferring the decision point: treatment assertions in neurology outpatient consultation. *Health Communication*. In Press.
19. Thompson L, McCabe R. How psychiatrists recommend treatment and its relationship with patient uptake. *Health Communication*. In Press.
20. Jones G. A communication model for dementia. In: Jones G, Miesen BML, editors. *Care-giving in dementia: Volume 1: Research and Applications*. East Sussex: Routledge; 1992.
21. Sugarman J, Roter D, Cain C, Wallace R, Schmechel D, Welsh-Bohmer KA. Proxies and Consent Discussions for Dementia Research. *Journal of the American Geriatrics Society*. 2007;**55**(4):556-61.
22. Karnieli-Miller O, Werner P, Aharon-Peretz J, Sinoff G, Eidelman S. Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics*. 2012:1-15.
23. Hasselkus BR. Three track care: older patient, family member and physician in the medical visit. *Journal of Aging Studies*. 1994;**8**(3):291-307.
24. Hamann J, Leucht S, Kissling W. Shared decision making in psychiatry. *Acta Psychiatr Scand*. 2003;**107**:413-09.
25. Bailey C, Dooley J, McCabe R. "How do they want to know?" Doctors' perspectives on making and communicating a diagnosis of dementia. *Dementia*. In Press.
26. Karnieli-Miller O, Werner P, Neufeld-Kroszynski G, Eidelman S. Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinic encounters. *Patient Education and Counseling*. 2012;**88**:381-90.
27. Campbell S, Manthorpe J, Samsi K, Abley C, Robinson L, Watts S, et al. Living with uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *Journal of Ageing Studies*. 2016;**37**:40-7.