

Title: How do doctors deliver a diagnosis of dementia in memory clinics?

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Abstract:

BACKGROUND: Dementia diagnosis rates are increasing. Guidelines recommend that people with dementia should be told their diagnosis clearly and honestly to facilitate future planning.

AIM: To analyse how doctors deliver a dementia diagnosis in practice.

METHOD: Conversation analysis was conducted on 81 video-recorded diagnosis feedback meetings with 20 doctors from 9 UK memory clinics.

RESULTS: All doctors named dementia. Fifty nine per cent approached the diagnosis indirectly but delicately ("*this is dementia*") while 41% approached this directly but bluntly ("*you have Alzheimer's disease*"). Direct approaches were used more often with people with lower cognitive test scores. Doctors emphasised that the dementia was mild and tended to downplay its progression, with some avoiding discussing prognosis altogether.

CONCLUSIONS: Doctors are naming dementia to patients. Direct approaches reflect attempts to ensure clear diagnosis. Downplaying and avoiding prognosis demonstrate concerns about preserving hope but may compromise understanding about and planning for the future.

Background

Worldwide government initiatives are strongly advocating an increase in dementia diagnoses to be made at earlier stages of the condition (1, 2). The National Institute of Clinical Excellence (NICE) states “People should be told their diagnosis as clearly and honestly as possible. Without this knowledge, people cannot begin to make sense of what is happening, nor can they plan effectively for their future” (3). The Memory Services National Accreditation Programme (MSNAP) publish standards for memory clinics, but do not address the communication of the diagnosis other than “the outcome of the assessment is communicated to all relevant parties in a timely manner” (4).

Previous studies have demonstrated that dementia presents a special set of considerations in breaking diagnostic news (5). Early symptoms are often noticed by family or friends who present to the doctor on the patient’s behalf (6). People with dementia may not acknowledge the extent of their difficulties and resist going to the memory clinic (7). Most will have impaired short-term memory, attention, and language processing and production (8). Currently in the U.K., the clinician communicating the diagnosis will often be meeting the patient for the first time at diagnostic feedback and will have no pre-existing relationship to guide the conversation (9). In the light of these complexities, the aim of this study was to micro-analyse video-recordings of diagnostic feedback consultations in memory clinics to describe how a diagnosis of dementia is communicated.

Methods

Data collection

Data were video recorded diagnostic feedback meetings collected through the NIHR funded Shared Decision Making in Mild to Moderate Dementia (ShareD) study (PB-PG-1111-26063). Data collection took place in 9 UK-based secondary care memory clinics in Devon (Site A – a semi-rural and rural setting) and London (Site B – an urban setting) from 2014-2015. The memory clinics followed the NICE pathway for dementia diagnosis (3), with specialist services performing brain scans, cognitive testing, and patient histories before meeting as a multidisciplinary team. Doctors fed back the diagnosis to the patient and management was discussed. In Site A, tests and feedback took place on the same day in a ‘one stop shop’ clinic. In Site B, the patient attended separate clinic visits for testing and diagnosis feedback.

All clinicians who delivered diagnoses in the participating memory clinics were approached. Consecutive sampling was used for patients. All patients attending the memory clinic for diagnosis feedback were eligible, except for patients needing interpreters due to the added complexity of the communication. Information sheets were sent with patient appointment letters, and researchers approached patients and their companions to obtain informed consent. Diagnostic feedback meetings were video recorded using Go Pro cameras. Camden and Islington Research Ethics Committee approved the study (13/LO/1309).

Data analysis

Data were analysed using conversation analysis (CA). CA is a method of micro-analysing verbal and non-verbal communication to provide insight into what people

say and how they say it. A transcription company transcribed the consultations verbatim. Sections related to the diagnosis were transcribed in detail for conversation analysis by the first author (57%) and a conversation analysis transcription company (43%) (10). Visual features such as gaze and posture were also analysed. This enabled a description of the structure of the diagnosis feedback meeting, as well as a detailed description of the practices doctors use to deliver dementia diagnoses. Independent sample t-tests were used where relevant to identify whether the use of different communicative strategies were linked with patient cognitive test scores.

The inclusion of data from different doctors in a variety of clinics, as well as comparison with studies of diagnosis deliveries in other settings, enhanced reliability (11). Validity was addressed through repeated analysis within and beyond the research team (12). Findings were discussed with participating doctors. This did not change the results but aided the analysis by contextualising the communication practices within service structures and cultures (13).

The CA transcripts presented have been simplified. The markers for prosody, stress and speed have been removed, leaving the markers for the overlapping speech (represented by square brackets) and length of silences (represented in seconds in brackets, with full stops representing pauses under 0.2 seconds).

Results

Participant characteristics

The consent rate for clinicians participating in ShareD was 88%. This dataset included 9 doctors from Site A and 11 from Site B. There was a mean of 4 patients per doctor, ranging from 1 to 9. There were 3 doctors where only one patient was recruited. Of 315 patients approached, 215 took part (62%). Of these, 101 patients were diagnosed with dementia, with the remaining patients being referred for further testing or receiving diagnoses of mild cognitive impairment, psychological conditions, or not receiving a diagnosis. The first 81 consultations of dementia diagnosis feedback were analysed in this study as part of a PhD project. Forty-three patients were from Site A and 38 from Site B. In 75% of meetings doctors were meeting patients for the first time.

Participant information is displayed in Table 1.

Table 1: Patient and Companion Characteristics

| Patient Characteristics | |
|---------------------------------------|------------|
| Age (mean, range) | 80 (52-92) |
| Gender: (n, %) | |
| Female | 47 (58%) |
| Male | 34 (42%) |
| Ethnicity: (n, %) | |
| White British | 61 (75%) |
| White Other | 8 (10%) |
| Caribbean | 3 (4%) |
| Asian Other | 1 (1%) |
| Black or Black British | 1 (1%) |
| African | 1 (1%) |
| Other | 3 (4%) |
| Missing | 3 (4%) |
| Diagnosis: (n, %) | |
| Alzheimer's disease | 47 (57%) |
| Mixed dementia | 13 (16%) |
| Vascular dementia | 12 (15%) |
| Dementia unspecified | 3 (4%) |
| Lewy body dementia | 3 (4%) |
| Parkinson's dementia | 2 (3%) |
| Semantic dementia | 1 (1%) |
| Cognitive Test Scores: (mean, range) | |
| ACE III (n=67) | 67 (27-94) |
| MMSE (n=8) | 22 (16-28) |
| Missing (n=6) | |
| Companion characteristics | |
| Minimum One Companion Present: (n, %) | 75 (92%) |
| Two companions | 6 (7%) |
| Three companions | 2 (2%) |

| | |
|---------------------------------|----------|
| Gender: (n, %) | |
| Female | 53 (64%) |
| Male | 30 (36%) |
| Relationship to patient: (n, %) | |
| Child/Child in law | 37 (45%) |
| Spouse/Partner | 29 (35%) |
| Other | 10 (12%) |
| Friend | 3 (4%) |
| Sibling | 3 (4%) |
| Missing | 1 (1%) |

Table 2: Doctor Characteristics

| Doctor Characteristics | |
|--|-----------|
| Gender: (n, %) | |
| Female | 11 (55%) |
| Male | 9 (45%) |
| Ethnicity: (n, %) | |
| White British | 13 (65%) |
| White Other | 3 (15%) |
| Asian or Asian British | 2 (10%) |
| Indian | 2 (10%) |
| Clinician Type: (n, %) | |
| Consultant Psychiatrist | 15 (75%) |
| Consultant Geriatrician | 3 (15%) |
| Specialty Doctor | 2 (10%) |
| Clinic Location: (n, %) | |
| London | 11 (55%) |
| Devon | 9 (45%) |
| No of Years working in Dementia (mean, range) | 12 (4-25) |

Structure of the diagnostic feedback meeting

Figure 1 displays the 5 core stages in the diagnostic feedback meetings, with the corresponding frequencies. Across the two sites there was less than 5% difference between these frequencies. In Stages 1 and 2 doctors elicited patient orientation to the meeting and their perspective on their symptoms. In Stage 3 the test results were fed back. The diagnosis was delivered in Stage 4. In Stage 5 treatment and management were addressed.

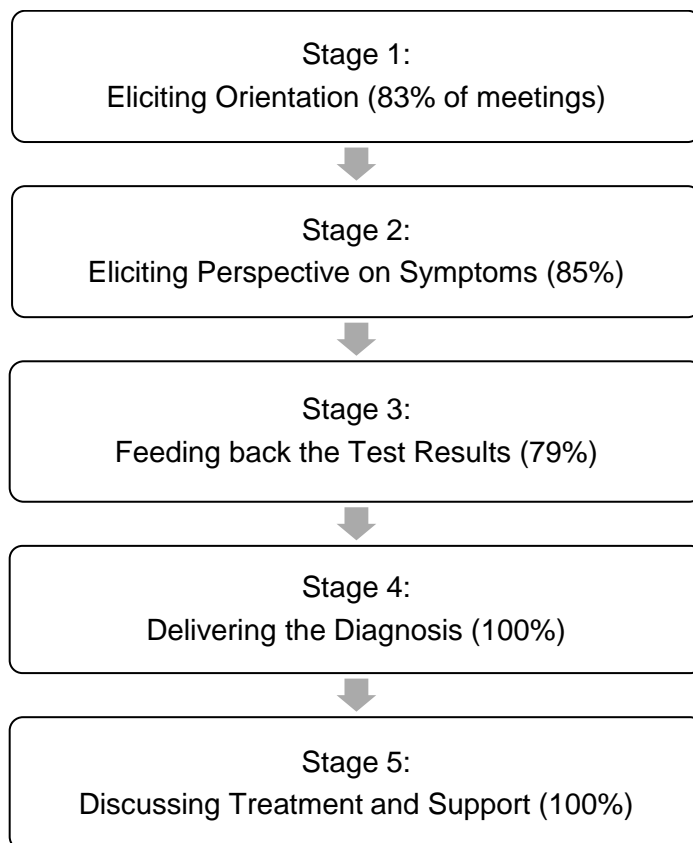


Figure 1: Stages of the Diagnostic Feedback Meeting

Communication of the Dementia Diagnosis

The communication of diagnostic information occurred in Stages 1-4 with systematic practices occurring across the 81 meetings. There was no significant difference in how often these practices were used in Site A and B. Additional examples of the practices described are available as supplementary material with the online publication of this article.

Stage 1: Eliciting Orientation to Diagnosis Feedback

In the majority of meetings doctors elicited the patient's orientation to the purpose of the meeting, often explicitly asking about the patient's expectations (Extract 1, line 1). If the patient did not display orientation, the doctor provided this information before proceeding (Extract 1, lines 4-10).

Extract 1

- 1 DR: **do you remember what this is all about today**
2 (0.9)
3 PT: er (0.6) no not really
4 DR: **ah well I'll tell ya**
5 (1.2)
6 DR: **you came here**
7 PT: mm[m]
8 DR: **[a] while back**
9 PT: that's right [yes]
10 DR: **[ab]out your memory**

As in Extract 1, 62% (n=50) of patients demonstrated some uncertainty as to the purpose of the diagnosis feedback at this stage of the meeting. While this could be attributed to short term memory loss, in some cases it was evident other factors were evident. In Extract 2, the patient does not respond after a significant pause (line 2) and her daughter explains she had told the patient that the meeting was for the brain scan results. The patient had therefore not been informed of the possibility of a diagnosis (lines 3-4).

Extract 2

1 DR: are you clear about what it- what the appointment is
2 (0.7)
3 DAU: no I just said it was obviously the results of the er
4 (.) the brain scan

Stage 2: Eliciting Perspective to Forecast the Diagnosis

Doctors elicited patient perspective on their symptoms, and then co-implicated their perspective in the diagnostic communication. This allowed doctors to ‘forecast’ the diagnosis prior to delivery. Forecasting is a tool that allows recipients ‘to estimate and predict what the news will be’, and thus ‘ultimately facilitates realisation’ (14).

In Extract 3, the doctor asks if the patient agrees that her memory is not “as good as it used to be” (lines 1-2). The patient shows some disagreement (lines 3-8). In these cases, doctors did additional work to demonstrate the problem: the doctor here presents test results that contrast with the patient’s view (lines 9-12). Doctors have

been found to present evidence in this way to manage potential resistance and prepare patients for diagnosis (14, 15).

Extract 3

1 DR: **do you think that that's right (0.4) that the**
2 **memory is not as good as it used to be**
3 (2.0)
4 PT: I don't think
5 (3.8)
6 PT: I don't think so but
7 DR: you don't think it's a problem
8 PT: it could be
9 DR: what I've heard is that (0.6) sometimes (.) you
10 know **I did some tests with you before (.)** some of
11 **the things were a little bit difficult on the memory**
12 **tests**

Conflict sometimes arose when doctors explored patient perspective while demonstrating prior knowledge of their situation. In Extract 4, the doctor's perspective elicitation includes symptom descriptions reported by the patient's daughter (lines 1-2, clarified in line 9 "family mentioned that"). The patient disagrees, indirectly questioning where the doctor got his knowledge ("I never said that", lines 4-8). When the doctor changes to an open question (lines 9-10) and the patient reports having good memory (line 12), the doctor takes a different tack asking if the patient has "any problems" (line 14). The patient then describes a single

recent incident (line 16), which, while still in conflict with the doctor and daughter's timeframe of 9 months, the doctor can still use to build up to the diagnosis.

Extract 4

1 DR: **from what I understand your memory problems started**
2 **about nine months ago?**

3 (2.8)

4 PT: no I've never said that- I've never said that

5 DR: no it's the yeah

6 (0.3)

7 PT: I've [never said fo-

8 DR: [probably]

9 DR: family mentioned that but in your (0.5) observation

10 (.) **how is your memory**

11 (0.3)

12 PT: good!

13 (0.3)

14 DR: **any problems?**

15 (1)

16 PT: only just recently when I lost my (0.8) oh my wallet

Stage 3: Feeding Back the Test Results to Forecast the Diagnosis

Doctors also forecasted the diagnosis in feeding back the test results by explicitly stating the patient has significant memory problems (Extract 5, lines 1-2, 4-5). This is an important part of the meeting as it may not be clear for patients which test provides the basis for the diagnosis (16).

Extract 5

- 1 DR: there were some **significant problems in a couple of**
2 **areas**
- 3 PT: mm
- 4 DR: **specifically around memory you were performing**
5 **below where we would expect**

Stage 4: Delivering the Diagnosis

All doctors named the dementia diagnosis in stage 4 of the meeting. The clear majority oriented their gaze and posture towards the patient on delivery, thus delivering the diagnosis to the patient and not their companion.

In 25% (n=20) of meetings doctors asked patients if they wanted to know the diagnosis immediately before naming the diagnosis as dementia (extract 6, line 1).

Extract 6

- 1 DR: **do you want to know what we'd call that memory problem**
- 2 PT: yeah
- 3 DR: yeah so we- we'd call it a vascular dementia

None of the patients explicitly stated they did not want to know their diagnosis, and thus in all these cases the diagnosis was named.

Two diagnosis delivery formats were identified in the analysis: indirect and direct. The indirect, more delicate, format was more common (59% of meetings; Extract 7, lines 1-3). It involves presenting the symptoms or test results and labeling them as 'dementia'. This format requires some patient inference: they have these symptoms, and these symptoms are dementia, thus they have dementia. In other settings, it is a common way of delivering diagnoses in order to avoid strong emotional or resistant responses (17).

Extract 7

1 DR: **the most common cause for** that kind of picture (0.4)
2 **and this kind of (.) picture on the (.) on the memory**
3 **tests (.) is a problem called Alzheimer's disease**

By contrast, the direct format (41%) involved directly attributing the 'dementia' label to the patient, by using phrases such as "you have" (Extract 8, line 1). A direct format requires less patient inference to understand the diagnosis, but is interactionally more blunt and thus likely to increase emotional or resistant responses (18).

Extract 8

1 DR: we think that **you have a dementia**

Most doctors used different formats for different patients, with 6 doctors using the same format for all their patients (excluding the doctors where only one meeting was recorded, n=3).

The relationship between the diagnosis format and patient scores on the ACE-III cognitive test was explored using an independent samples t-test. Too few patients were assessed on the MMSE to analyse these scores. ACE-III scores were lower among patients with whom doctors used a direct (mean score=64, SD=13.32) versus an indirect format (mean score=71, SD=13.31) ($t(63)=2.07, p=0.042$).

Although the evidence for a diagnosis had been presented prior to naming dementia, doctors often re-referred to the evidence in the diagnostic utterance (55%; Extract 9, lines 1). Explicating the evidence makes the doctor's reasoning more visible and tends to be used in the face of potential resistance (15). This may also assist understanding among those with difficulty holding information in short term memory.

Extract 9

1 DR: **because of the changes we've seen in your scan** (0.4)
2 I think the most (.) likely cause (0.6) is (0.4) er is
3 one of vascular dementia

The diagnosis was often characterised as uncertain (38%) by doctors using phrases such as "the most likely" or "this probably is" (Extract 10, line 1).

Extract 10

1 DR: **the most likely diagnosis that we can come up with** is a

2 mild Alzheimer's dementia

An emphasis on dementia as a “condition” or “illness” was also common (49%; Extract 11, line 1). Emphasising that dementia has a medical cause delineates symptoms from ‘just old age’, which is commonly how people explain dementia symptoms (19).

Extract 11

1 DR: what you've got is **a condition called** Alzheimer's
2 disease

Doctors were seen to reassure patients that they had “mild” dementia, including when patients scored well below the cut-off point on cognitive tests (42%; Extract 12, line 1). This enabled doctors to frame the diagnosis positively, and differentiate the patient's situation from negative images of late stage dementia.

Extract 12

1 DR: it's looking like **an early form of a dementia**
2 PT: yeah

Stage 4: Delivering the Diagnosis by using Good News Exits

Doctors used good news to exit the diagnosis discussion, emphasising the positive aspects of receiving treatment and support (53%). This involved describing an ‘optimistic projection’ of the patient's future (20). In Extract 13, the doctor delivers the diagnosis and pursues a response by providing more information (lines 1-5). The

patient passes up two opportunities to speak (lines 2, 5) and the doctor progresses to assess the diagnosis as “good” because the patient will be able to start medication (lines 6-14).

Extract 13

1 DR: you probably have early Alzheimer's disease
2 (0.6)
3 DR: which is a disease in the brain which affects
4 memory
5 (1)
6 DR: um (0.8) and (.) I think that's (.) **it's good**
7 **to start thinking about that as a possibility**
8 **because there are some (.) things that we can try to**
9 **do**
10 (0.3)
11 **medications that we can try**
12 (.)
13 **which can help to (0.6) slow down the progression of**
14 **the memory problem**

Stage 4: Delivering the Diagnosis – Discussing Prognosis

Prognosis was explicitly discussed in 62% of meetings and was approached sensitively with qualifications. In Extract 14, the doctor talks generically – “generally speaking” (line 1) “for most people we expect it to get a little worse” (lines 4-5) – rather than describing specifics. The deterioration is minimised, saying the dementia will get “a little worse” (lines 4-5) over “many years normally” (lines 7-8).

Extract 14

1 DR: **generally speaking** this is a condition that changes
2 over time
3 PT: mhm [mhm]
4 DR: [and] **for most people** we expect it to get **a little**
5 **worse** over time.
6 (0.5)
7 DR: but that means (.) **over the space of many years**
8 **normally**

Prognosis was not discussed in 14% of meetings. In 24% of meetings, prognosis was indirectly invoked when discussing the potential of medication to “slow the progression of this memory problem” (Extract 15, lines 3-4).

Extract 15

1 DR: now what I wanted to talk to you about (.) today (0.4)
2 among other things (0.3) was that we do have some
3 medication (0.4) **that could slow (.) the progression**
4 (.) of this memory problem

Medication was not offered to patients in 17% of the meetings, due to their diagnosis not being eligible for treatment using cholinesterase inhibitors. Prognosis was discussed explicitly in 71% of these meetings (n=10/14), a higher proportion of those where medication was discussed (60%, n=40/67).

Discussion

All doctors in the study clearly named dementia. Doctors deployed specific strategies to make the diagnosis clear to patients, but often downplayed or avoided prognosis.

Doctors elicited patient orientation to the purpose of the meeting. This has not been described in work examining the structure of primary care consultations (21), indicating that orientation is generally assumed in primary care but not in memory clinics. Over 60% of patients showed some uncertainty about the meeting purpose, which may be due to patients having non-medical symptom explanations and companions being more proactive in seeking help (22). Additionally, as shown in Extract 2, patients may not be informed as to the purpose of the diagnostic meeting. When patients do not expect a diagnosis, this can lead to more distress (23) and difficulty accepting the diagnosis and its consequences (24). Hence, eliciting orientation and forecasting the diagnosis prior to diagnosis delivery is important. However, guidelines advocate patient preferences for information should be ascertained prior to the diagnostic feedback meeting (25). Given that in 20% of meetings the doctors were asking if patients wanted to know the diagnosis immediately prior to delivery, this may not be happening in practice.

The common use of direct deliveries (“you have dementia”) is different from cancer or HIV, where they are considered blunt and less sensitive (18, 26). That direct deliveries occurred more often when patients had poorer cognitive functioning suggests doctors are overriding the normative, sensitive approach for a more blunt approach that may enhance understanding. Doctors also clarified the diagnosis by

restating the evidence and differentiating the diagnosis from normal ageing. However, as the number of consultations is relatively small per doctor, it was not possible to analyse how doctors varied their approach with different patients. Additionally, previous work examining dementia diagnosis delivery has shown other aspects of communication, such as fractured sentences and hesitations, may negatively affect understanding (5), an aspect that was not explored in this study. Further work examining patient responses with a larger dataset, both before and after the consultation, would be necessary to draw conclusions on the effect these factors have on patient understanding and their emotional response.

That doctors are using strategies to enhance diagnostic understanding contrasts with previous research, which illustrates doctor avoidance of dementia diagnosis discussions (27, 28). While this may be due to the presence of video cameras, a study using video recordings by Peel et al illustrated systematic avoidance of the 'dementia' label in data collected in 2012 (28). This may reflect a cultural shift, potentially because of campaigns such as the National Dementia Strategy that have emphasised the importance of receiving a diagnosis so people can plan and access support. These campaigns are having an effect on the perception of dementia amongst both the public and clinicians (29, 30), which may be improving open diagnostic communication.

Indirect allusion to, avoidance of, and downplaying prognosis has been found previously in dementia (5) and other settings (31) where doctors often follow diagnostic news with positive discussions of treatment (32, 33). While this could be

compounded by the fact not all people with dementia are eligible for medication, explicit discussions of prognosis occurred in slightly more meetings where medication was not offered. This indicates that a lack of treatment may not be the only reason that prognosis is avoided. While how much people want to know will vary (24), avoiding the subject means people may miss the chance to plan for their future (34). There have been initiatives to engage people in advance care planning at diagnosis, but doctors reflect that this is too early (35). However, given concerns that appropriate post-diagnostic support is not always available, if prognosis is not discussed at diagnosis people may have difficulty coping as the dementia progresses (36). More work is needed on how and when prognosis should be discussed.

Patients and companions will have a variety of explanations for dementia symptoms, from biological descriptions about brain changes, to social factors such as living alone, to psychological factors such as stress (7, 37). These may affect how doctors communicate and also how patients and companions respond and adjust to the diagnosis (37, 38). While the diagnosis in this study was primarily delivered to patients (as judged by gaze on delivery), research has shown that companions become increasingly involved in treatment and support discussions (39). While this study did not analyse the role of the companion in detail, where patient and companion expectations differ, there is potential for more difficult communication: in Extract 2 the daughter had withheld the purpose of the meeting from her mother, and in Extract 3 the daughter had given the doctor information that the patient did not agree with. These pre-existing relationship dynamics are an additional challenge for doctors when communicating the diagnosis (27).

Although this study reports a microanalysis of diagnosis delivery, it reflects wider discussions about what people want from a dementia diagnosis. Patients and companions prefer honesty but want to maintain hope (40). Providing this balance is a complex task, combining practical and moral dilemmas (41). Preferences for how, when, and what information should be shared vary greatly (25). In general, doctors receive little training in diagnosis delivery beyond basic breaking bad news training, with most not receiving training specifically in psychiatry or dementia (9). Doctors report wanting to communicate information that is tailored to the individual, but find this difficult when meeting the patient for the first time, which applied to 75% of meetings (9). Additionally, provision of support and advice as the illness progresses is also extremely important (25). Conceptualising assessment and communication of a dementia diagnosis as a process, rather than a single event, is therefore integral.

The strengths of this study come from a rigorous qualitative analysis of a large dataset, with a variety of different doctors, in specialist memory clinics in two different geographical areas. However, the sample did not extend to primary care or other settings where a diagnosis may be delivered. Additionally, all the clinicians in the study were medical doctors, and different healthcare professionals may approach the diagnosis differently. While the consent rate of 62% is high for this study type, the 38% who declined may differ from those who participated, which may affect generalisability. Not all types of dementia or different ethnic and cultural groups were represented. The presence of cameras may have altered doctor

communication. Finally, it was beyond the scope of this paper to analyse how patients responded to the diagnosis, or the role of the companions.

In conclusion, doctors are clearly naming dementia but are more variable in discussing prognosis. Further work is needed to explore the ethical issues involved in communicating the degenerative nature of dementia in the diagnostic feedback meeting, as well as what information at this stage will facilitate planning for the future whilst also preserving hope.

Acknowledgements

We thank all the patients, companions and healthcare professionals who allowed us to film the consultations, as well as Professor Gill Livingston and the Shared project team.

Funders

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-1111-26063), and supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South West Peninsula. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Conflict of Interest

None

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