



# City Research Online

## City St George's, University of London

**Citation:** Bailey, C., Dooley, J. & McCabe, R. (2019). 'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia. *Dementia*, 18(7-8), pp. 3004-3022. doi: 10.1177/1471301218763904

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

**Permanent repository link:** <https://openaccess.city.ac.uk/id/eprint/21706/>

**Link to published version:** <https://doi.org/10.1177/1471301218763904>

**Copyright and Reuse:** Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to [City Research Online policy](#).

# “How do they want to know?” Doctors’ perspectives on making and communicating a diagnosis of dementia

Key words: Dementia diagnosis, memory clinic, communication

## Abstract:

Recent drives to facilitate earlier identification of dementia have led to increased memory clinic referrals and diagnoses. This study explored the perspectives of memory clinic doctors on making and delivering diagnoses.

Four focus groups were conducted with 13 psychiatrists and 2 geriatricians in the U.K. Transcripts were coded line by line using NVIVO. Thematic analysis identified 39 categories, 18 sub-themes and 8 overarching themes. Inter-rater reliability on 31% of the data was 0.89.

Increased public awareness of dementia was viewed positively in facilitating access to diagnosis and treatment. Doctors viewed diagnosis as a process and expressed concerns about limited pre-diagnostic counselling and post-diagnostic support. In diagnostic delivery doctors sought to develop a narrative drawing on the patient’s report of symptoms and adjust explanations to patient preferences and awareness. However, tailoring the delivery to the individual patient was challenging when meeting for the first time.

These consultations often involved three participants (doctor, patient and relative), who were felt to have differing needs and expectations. Doctors emphasized that delicacy was required in deciding in what could be discussed in front of both parties, however also stressed the importance of explicitly naming “dementia”. Efforts were made to balance honesty and hope when discussing prognosis and medication. The work was sometimes emotionally distressing, with limited supervision. Existing communication training was felt to be inadequate for consultations involving triads or people with cognitive impairment.

Delivering a dementia diagnosis is a nuanced and challenging task. Negotiating honest descriptions of a life-limiting condition whilst instilling hope is further complicated when cognitive impairment affects comprehension. Misunderstandings at the time of feedback may limit patient opportunities for informed future planning afforded by early diagnosis. Doctors in memory clinics would benefit from evidence based training and supervision to prepare them for these emotionally challenging and complex consultations.

297 words

## Introduction:

Dementia policy and care has changed dramatically in the last 20 years. Memory clinics were first established in the UK in the 1980s, however the introduction of cholinesterase inhibitors in the 1990s led to their proliferation (Lindesay, Marudkar, van Diepen, & Wilcock, 2002). Diagnostic memory clinics are now recommended as the single point of access for people with possible dementia (NICE, 2016).

The 2009 Prime Minister's Challenge sparked further policy changes, emphasising the importance of earlier diagnosis (Department of Health, 2016). Early, or "timely", diagnosis is now an audit target for memory clinics (RCPsych, 2016). A diagnosis in the initial stages of the disease process may allow the person to express preferences for future care whilst they retain capacity (NICE, 2016) and access to pharmacological and psychosocial interventions, which may lengthen community independence (Leung et al., 2011). The drive for early diagnosis has increased memory clinic referrals, and more patients attending with milder symptoms (Hodge & Hailey, 2015).

Breaking bad news situations, such as delivering dementia diagnoses, are thought to be a communicative dilemma (Del Vento, Bavelas, Healing, MacLean, & Kirk, 2009). Begley and Blackwood (1998) describe the quandary as one of 'truth-telling vs hope'. Observational studies of memory clinic dementia feedback appointments find doctors demonstrate anxiety, use mitigating language and avoid emotional exploration or clarification of the diagnosis (Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 2007). Doctors also report 'flexibility' in their diagnostic language and employ euphemisms to try to reduce distress (Kissel & Carpenter, 2007; Phillips et al., 2012). Del Vento and Bavelas et al (2009) suggest such 'implicit' methods rely on the patient interpreting the information within the conversational context, which could potentially be problematic for patients with cognitive impairment.

A small observational study of 5 patients during memory clinic consultations in 2015 found that doctors tended not to explicitly name "dementia" or "Alzheimer's Disease" (Peel, 2015). However, a more recent study of UK memory clinics found that doctors consistently named dementia when delivering the diagnosis (Dooley, Bass, & McCabe, 2018). This may potentially reflect an increasing culture of disclosure in recent years (Hellstrom & Torres, 2013).

There is a growing literature exploring breaking bad news of other diagnoses such as cancer (Maynard & Frankel, 2006). In primary care consultations doctors have been noted to shroud the information, and focus on a medical discourse which has been interpreted to be an attempt to avoid uncontained emotional responses in patients (Maynard & Frankel, 2006). However, in addition to the task of conveying bad news, memory clinic consultations present specific communicative challenges. Firstly; patients have varying degrees of cognitive impairment. Dementia impedes communication through problems with word finding, comprehension and short-term memory (Blair, Marczyński, Davis-Faroque, & Kertesz, 2007). In addition, presumptions of incapacity can sometimes lead to people with dementia being marginalised (Karnieli-Miller,

Werner, Aharon-Peretz, Sinoff, & Eidelman, 2012). Furthermore, diagnosis feedback in memory clinics is frequently multi-party: patients attend with a relative or friend. Although companions represent increasingly important support for a person with dementia, their presence can create challenges for the professional in balancing the needs of both parties (Robinson, Bamford, Briel, Spencer, & Whitty, 2010), and clinicians have minimal communication training in negotiating triadic consultations (Robinson et al., 2010).

Existing literature highlights the challenge of providing clear diagnostic information whilst remaining sensitive to the emotional experience of the person with dementia and their companion (Dhedhi, Swinglehurst, & Russell, 2014; Dooley, Bailey, & McCabe, 2015; Hansen, Hughes, Routley, & Robinson, 2008). Patients and families often feel diagnoses are not adequately explained, leaving uncertainty about the future and where to access support (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). However, there is a lack of evidence-based guidance on how doctors should communicate in these settings (Holloway, Gramling, & Kelly, 2013).

A diagnosis of dementia is recognized as a process rather than a single event (Hellstrom & Torres, 2013). However, the diagnosis feedback meeting represents a crucial stage in this journey. Doctors' experiences of making and communicating a diagnosis in memory clinics have not been explored (Robinson et al., 2010). The aim of this study was thus to investigate the views and experiences of doctors making and delivering diagnoses in memory clinics.

## Methods:

### Design:

Four focus groups were held in London and Devon between October 2014 and March 2015. They were conducted as part of the ShareD (Shared Decision Making in Dementia) study, which is analysing diagnosis delivery and shared decision making in mild to moderate dementia. A fifth focus group was held in January 2016 to further explore and validate preliminary findings.

Each group lasted approximately 1.5 hours. The topic guide was developed to address issues identified in a systematic literature review (Dooley et al., 2015). It was reviewed and adapted by the Alzheimer's Society Research Network of people with dementia and their families. The first four focus groups were conducted before transcription and analysis occurred. However, phrasing of questions and particular focus within the groups did evolve in response to themes emerging from the preceding groups.

A summary of core questions is found in **Table 1**.

Table 1. Focus Group Topic Guide

<p><b>Communication of a diagnosis:</b></p> <ol style="list-style-type: none"><li>1. What needs to be discussed in the diagnostic feedback session?</li><li>2. How do you approach giving the diagnosis?</li><li>3. Who is the primary recipient of the diagnosis?</li><li>4. Are there particular diagnoses which are difficult to communicate or seem to create confusion?</li><li>5. Are there situations in which you do not disclose the diagnosis to the patient? Or are there times where you avoid using the words 'dementia' or 'Alzheimer's disease'?</li><li>6. Have you received any training in how to deliver a diagnosis?</li><li>7. How are you emotionally affected by giving the diagnosis? What strategies or support do you have for managing your own emotions?</li><li>8. Are there structural or systemic issues which create issues for making or communicating a diagnosis?</li></ol>
<p><b>Shared decision making:</b></p> <ul style="list-style-type: none"><li>• What does shared decision making mean in the memory clinic? Who are you sharing the decisions with?</li><li>• How can you tell if patients want to be involved in decisions? How do you ascertain a patient's decision-making preferences?</li><li>• How does the presence of carers or companions impact on shared decision making or patient involvement in decisions?</li><li>• Does it make any difference depending on relationship of the carer to the patient (eg: adult child, or elderly spouse)?</li><li>• When is the right time to discuss about advanced care planning?</li><li>• How confident do you feel continuing to involve people in decisions when they lack capacity?</li><li>• What are some of the difficulties inherent to facilitating shared decision making in the memory clinic?</li></ul>

The focus groups were video recorded and facilitated by first and third authors. The SharedD study was granted ethical approval by the Camden and Islington Research Ethics Service (13/LO/1309) and participants gave written informed consent.

### **Setting and Participants:**

Thirteen old age psychiatrists (trainees, specialist registrars or specialty doctors) and 2 geriatricians were recruited through their involvement in the SharedD study. All were engaged in making and delivering diagnoses in memory clinics. Participant characteristics are described in **Table 2**.

Table 2. Participant Characteristics

Participant Characteristics	
Gender:	
Female	4 (27%)
Male	11 (73%)
Ethnicity:	
White British	11 (73%)
Indian	2 (13%)
Other White Background	1 (7%)
Pakistani	1 (7%)
Clinician Type:	
Consultant Psychiatrist	9 (60%)
Specialty Doctor	3 (20%)
Consultant Geriatrician	2 (13%)
Core Trainee in Psychiatry	1 (7%)
No of Years working in Dementia	14 (4-25)
Clinic Location:	
East London	6 (40%)
Devon	6 (40%)
North London	3 (20%)

### Analysis:

Interviews were transcribed by the first and second authors before thematic analysis was conducted (Braun & Clarke, 2006; Huberman, 1994). Transcripts were coded line-by-line using NVIVO 11. All authors developed codes jointly in 12 meetings. Nineteen percent of the data was jointly coded by all authors. The remaining data was coded by first author.

A process of data reduction and display was undertaken by first author using NVIVO and Excel (Huberman, 1994), generating categories, sub-themes and themes. These were reviewed by all authors in 14 analytic meetings. Differences of opinion were resolved through discussion. Final themes were agreed upon by all authors. Once themes were finalised a further 31% of the data was coded by second author. Inter-rater reliability was calculated on this data by applying categories to the raw data yielding an agreement of 0.88.

Direct quotations were selected to illustrate the themes and diversity of views within the focus groups. The participants are anonymously identified with a number, eg: P4.

### Results:

From 716 codes 39 categories were identified, which fed into 18 sub-themes and 8 overarching themes. Themes and sub-themes are discussed below and summarised in **table 3**.

Table 3. Sub-Themes and Themes

Sub-Themes	Themes
Media portrayals, stigma, and dementia as a political agenda	Public awareness and the political agenda: service and individual responses
The evolving remit of memory services: managing increasing referrals	
Making an accurate diagnosis with limited time and information	Making and delivering a diagnosis: challenges, strategies and utility
The utility of a dementia diagnosis	
Triadic dynamics: old patterns, new stresses	Playing to two audiences
Doctors' shifting alliances: Balancing patient and companion needs and involvement	
The complex, shifting role of companions: insight, expectations and attributions	
Limited training and support for the complex and emotional task	Breaking bad news: application and suitability of existing frameworks and training in memory clinics
Context and preparation: assessing patient insight and readiness for the diagnosis	
The process of diagnosis delivery: considered use of labels, building personalised narratives	
The spectrum of insight and interest in the diagnosis	The range of insight, engagement and emotional reactions to diagnosis
Varying emotional responses to the diagnosis and its practical implications	
Instilling hope: the uncertain efficacy of medication and the message of living well	Balancing honesty, hope and uncertainty
Communicating practical implications and prognostic uncertainties	
Information provision and cognitive impairment	Shared decision making: capacity, cognitive impairment and companion involvement
Shared decision making: triadic communication within the context of pre-existing relationships	
Service and personal strategies for maximising continuity within the memory clinic structure	Providing continuity of personalised care within service constraints
Balancing personalisation and flexibility with institutional agendas	

### Public awareness and the political agenda: service and individual responses

The doctors discussed the impact of the raised profile of dementia in the media, changing policies and political agendas. They described the varying service level and personal responses to increased referrals, and targets which did not always seem to reflect patient needs.

#### *Media portrayals, stigma, and dementia as a political agenda*

Participants felt the prominent profile of dementia in the media had increased public awareness. Frequent comparisons were drawn to the evolution of cancer from being hidden and stigmatized, to being openly discussed.

*"More people say "have I got dementia?" than maybe a few years ago. You'd have to skirt around it." – P7*

However, media reports were thought to falsely elevate the treatment expectations of patients.

*"Every week in the Mail or the Express there's a 'X' cures dementia. I think they've built up (expectations) beforehand. And what you're doing is being realistic." – P9*

### *The evolving remit of memory services: managing increasing referrals*

The ageless and accessible nature of memory services meant they became a 'catch all' route into mental health systems. There was a sense from the doctors of increasing inappropriate referrals, such as younger adults with clearly diagnosable depression (rather than any suggestion of neurodegenerative disorder) or those actively consuming large amounts of alcohol.

*"The memory clinic has sort of become an easy way for people under 50 to be seen quickly (by mental health services)." – P15*

Efforts to streamline diagnostic processes were felt to reduce personalisation and continuity for patients. The governmental focus on diagnosis was thought to have neglected adequate funding for post-diagnostic support.

*"All kinds of ill thought out dementia screening initiatives, lots of talk of increasing diagnostic rates and coding and registers, but no talk of psychosocial intervention. No talk about the sort of predations on budgets and social services delivering the very things we know will help these people." – P13*

### **Making and delivering a diagnosis: challenges, strategies and utility**

The doctors considered the challenges and factors involved in the diagnostic process, as well as the utility of a correct and timely diagnosis.

#### *Making an accurate diagnosis with limited time and information*

Doctors spoke of the structure in some memory clinics being organized so that allied health staff conducted the initial memory clinic assessment, including history taking and cognitive testing. This meant doctors were often delivering diagnoses to patients they were meeting for the first time, having not completed the assessment. This felt unnatural, and also meant the skills of other clinicians could affect diagnostic clarity.

*"You're at the mercy of the person who's taken the history, and that can be variable at how skilled the person is at probing and getting to the bottom of things." –P4*

Some anxiety about entering the diagnostic process at the end stemmed from not knowing the patient's readiness, understanding and expectations.

*"If I'm going to give someone a diagnosis of Alzheimer's I would normally spend the first half hour of the assessment getting the information, but also working out who's in front of me." – P5*

Mild Cognitive Impairment (MCI) diagnoses caused contention in terms of the disease as an entity, the prognosis, and how to communicate this.

*"Sometimes I think a diagnosis of MCI can be difficult to explain because people can catch the wrong end of the stick. They think it's completely normal and you're having to explain that as a diagnostic entity itself it has a lot of uncertainty around it." - P2*

### *The utility of a dementia diagnosis*

Diagnosis was considered useful in unlocking support options for patients and families and helping the person with dementia understand their experiences.

*"The diagnosis, the label, and severities; sharing that with all the right stakeholders – social services if necessary, mental health, physical health, GP. I always see that as a really important outcome." – P10*

*"I say that it helps other people to understand what you're finding difficult and to make plans to help you to deal with it." – P6*

Although medication was often introduced first in treatment discussions, other supportive therapies were felt to perhaps be even more important.

*"I present the Cognitive Stimulation Therapy basically along the same lines as the cholinesterase inhibitors. And I sometimes say that they're sort of similarly effective." – P15*

### **Playing to two audiences**

The doctors described communicating within triads (doctor, patient and companion) and how this required a delicate approach to manage the needs and expectations of all participants.

#### *Triadic dynamics: old patterns, new stresses*

The triad contained both challenges and resources, and was experienced as a system of old patterns of behaviour under stress of new symptoms of dementia. Doctors were "playing to two audiences" (patient and companion) (P4) with differing needs. Being "parachuted in" (P9) at the diagnosis stage sometimes represented an opportunity. Doctors could, after observing interactional dynamics, "hold a mirror up" (P6) and intervene in a difficult family situation. Others felt scrambling to grasp the family context was a challenge.

*“Sometimes the carers are angry with the person (with dementia), thinking they’re not trying hard enough or that their behaviour is purposeful. It’s at that point you sort of swing away from making the decisions to thinking about the dynamic between the two of them.” – P1*

### *Doctors' shifting alliances: Balancing patient and companion needs and involvement*

Balancing the needs and involvement of all participants in the triad sometimes led to conflict. Doctors were attuned to detect subtle cues of carer burden, whilst remaining mindful of the potential for patient marginalisation.

*“Sometimes the relative wants you to say something that they can’t say, or they’ve been trying to say for some time. So there’s a lot of sort of picking up on work to do before you get to the actual diagnosis.”- P4*

*“It’s difficult when they disagree. You don’t want to be put in the position where you’re advocating for the carer and the person with the diagnosis feels attacked.” – P2*

### *The complex, shifting role of companions: insight, expectations and attributions*

The role of companions varied, with observations of advocacy, support, and protective caregiving. The doctors felt an important aspect of the consultation was to correct companion misunderstandings or attributions about the symptoms of dementia.

*“...To try to help the carer understand that the person isn’t doing it on purpose, or even if it’s a reflection of their previous personality they’re not so able to control their previous personality as before. Sometimes the carers are angry and that’s really difficult.” – P1*

### **Breaking bad news: application and suitability of existing frameworks and training in memory clinics**

The doctors considered how existing approaches to breaking bad news may or may not be relevant or demonstrate utility in delivering a diagnosis of dementia.

#### *Limited training and support for the complex and emotional task*

Only a few doctors had received specific training in delivering dementia diagnoses. Many described relying on the basic principles taught in medical school, which did not always easily apply.

*“I remember being filmed in medical school and it being about telling an actor playing the role of a wife that her husband had died. So, it’s a very different kind of scenario to giving a diagnosis of dementia to someone. I don’t think it necessarily translates naturally to this setting.” – P2*

Lack of supervision and opportunity to discuss the emotional aspect of the work was frequently discussed.

*"The point is that there is a lot of pain and angst. How do we deal with it? The litany of the patients that have to be told, the number that have to be told that they've got an incurable illness." – P13*

### *Context and preparation: assessing patient insight and readiness for the diagnosis*

Patient readiness, expectations and interest were key in tailoring the delivery. Meeting for the first time in feedback added to the uncertainty of how the patients would receive a diagnosis.

*"How do they want to know?" – P5*

*"It depends on the signals you pick up from people. Some people will walk through the door and say, 'just tell me'. There are other people who come in not expecting it at all and you obviously have to change your approach." – P3*

*"You can't deal with your medical agenda until you tell the patient's agenda. Establishing they're there in order to receive the diagnosis is paramount. If they don't know that's why they're there, you haven't even got to first base." – P15*

### *The process of diagnosis delivery: considered use of labels, building personalised narratives*

Efforts were made to develop a personalised narrative when communicating the diagnosis. This included linking the diagnosis to particular symptoms in the history, as given by the patient.

*"Depending on the sort of rapport and impression you get, involving them in the thought process that brought you to the diagnosis. Explaining a little bit about your interpretation of the investigations and the significance in the greater context." – P3*

Specific attention was given to the placement of the words 'Dementia' and 'Alzheimer's'. Some described a "circuitous route" (P4), where they would speak of 'memory problems' or other euphemisms initially; introducing 'dementia' later when discussing treatment. However, all reported using the word 'dementia' in most consultations and the decision about timing was in response to patient cues. Some occasionally avoided the words; instead employing euphemisms due to stigma, fear of causing emotional distress, and sometimes an awareness that particular terms had little meaning in some cultures.

*"I skirt around it with some people. I still talk euphemistically about 'memory problems' for quite a long time" - P4*

*"It's a little dance, isn't it; using the appropriate language at the time." – P7*

### **The range of insight, engagement and emotional reactions to diagnosis**

The doctors described observing varying degrees of patient awareness, interest and reactions to the diagnosis and discussed how they adjusted their communication approaches.

#### *The spectrum of insight and interest in the diagnosis*

Despite patients generally presenting earlier in the disease process, doctors witnessed varying degrees of insight. They attributed these differences to the anosognosia associated with neurological conditions, and a psychological level of denial. When patients were disinterested, the doctors were aware of directing their communication more towards the companion.

*"The more progressed they are with the dementia the more difficult it is for them to engage fully in the whole process of feedback. Sometimes it's difficult not to give all the floor time to the relative. It's the relative that's more distressed, because you know there may be frontal lobe involvement and there's that agnosia element of Alzheimer's disease where people are sort of aware but they're not aware." – P13*

#### *Varying emotional responses to the diagnosis and its practical implications*

Patients who seemed unmoved by the diagnosis were those who had been disinterested initially. However, occasional instances of extreme 'hostility' (P3) were observed.

*"I had a wife who had Alzheimer's who dragged her husband from the room saying 'We're not listening to this, come on'. I think she was just utterly terrified of the diagnosis. So in the end we got nurses involved, went very tentatively and we did it at home." – P5*

Discussions about driving were often the point of most distress. The doctors thought this might represent the first loss of independence; more concrete and tangible than the concept of dementia itself.

*"I think it varies with the individual. Some people feel if you're talking with them about giving up driving that you're taking away everything; their life, their autonomy. So I think that's a really difficult thing to do. That can be more difficult than the diagnosis because they often can't remember that (the diagnosis)." – P1*

### **Balancing honesty, hope and uncertainty**

Frequently described in the focus groups was the dilemma of balancing an honest description of a neurodegenerative, life-limiting disease, whilst still offering hope and acknowledging the difficulty in predicting prognosis.

#### *Instilling hope: the uncertain efficacy of medication and the message of living well*

The doctors articulated tension between honesty, hope and uncertainty in communicating diagnostic, prognostic and treatment information. Varying styles were discussed including a blunt but clear delivery, and a more optimistic approach that may lead to confusion.

*“There is a stronger urge that you have to resist to be overly positive, to avoid the negativity altogether. It’s natural to try to ease the blow as much as you can but you don’t want people leaving without understanding.” – P3.*

*“The purpose of the feedback, for me anyway, is to deliver the diagnosis, and actually, you know, say it – ‘the D word’ – and give it to the patient and their carer...you offer the diagnosis and then you have to do some reparation”. – P13*

The feedback appointment was about helping the patient to begin to understand the diagnosis, but that fully grasping the disease trajectory might be overwhelming.

*“I want them to understand, but not to understand too much. It’s important to know that it doesn’t mean that tomorrow you’ll be the person who can’t talk, can’t move, can’t walk.” – P1*

The doctors were conscious of using medication to soften the blow of the diagnosis. Whilst many felt ambivalent about the efficacy of cholinesterase inhibitors, they described their action as a metaphor; communicating hope.

*“I think from the moment one starts talking about treatment, it already has a placebo effect on the actual adjustment or stress reaction of the patient.”. – P15*

### *Communicating practical implications and prognostic uncertainties*

Communicating prognostic information was a particular challenge, in part due to the uncertain illness trajectory. There was a difficult balance between correcting misunderstandings that dementia immediately resulted in complete dependency, and offering false hope by avoiding prognosis discussions. Many felt some optimism was vital, and the overarching message should be one of opportunity to plan for the future.

*“There’s something about not letting the diagnosis swamp them, that they’re still the same person tomorrow, with a bit more baggage and that you can, as you say take control of it, make decisions, continue going on your cruise.”– P5*

### **Shared decision making: capacity, cognitive impairment and companion involvement**

Making decisions within triads was explored in terms of how cognitive impairment and relationships can affect capacity, and the challenges of limited time and prior knowledge of the patient.

### *Information provision and cognitive impairment*

There was an awareness of the limitations of what patients and companions can take away from the consultation. Challenges and strategies for communicating information to patients with cognitive impairment were discussed.

*"I often try and include them both quite explicitly. So look at the person with dementia and say 'I know you won't remember all of this but your husband, your daughter who is here and they will also act as your memory and will remind you.'"*  
– P1

### *Shared decision making: triadic communication within the context of pre-existing relationships*

The need to understand the patient's preferences was highlighted. A desire to delay decisions to allow deliberation was often offset by systemic pressures, including lack of continuity, time and uncertain follow up. This was further compounded by grappling with the pre-existing patient-companion relationships and meeting for the first time.

*"There's quite a lot to fit in there, but if you can't remember what I just told you there's no point trying to pretend that you're deciding, and then deliberately going over to the relative and having some kind of quickly shoehorned-together best interest decision."* – P10

### **Providing continuity of personalised care within service constraints**

The doctors all worked in memory clinics where the patient pathway was triggered by a referral, resulting in an assessment, diagnosis and diagnostic feedback. The care following diagnosis was variable but ranged from immediate discharge to the GP, nurse led medication reviews or the treating doctor seeing the patient for a single review. The doctors discussed individual and service level approaches to trying to provide continuity and patient-centred care in a setting where diagnosis was the primary focus.

### *Service and individual strategies for continuity within memory clinic pathways*

Meeting patients for the first time also represented part of a wider challenge to provide continuity of personalised care, from the level of the individual doctor, working within a wider system.

*"If I'd done an initial assessment on somebody I know them much better and give them better care than if somebody else has assessed them. Obviously there's this tension with service provision versus quality of care. If you want genuine shared decision making and high quality care you've got to allow people to get to know to know people."* – P5

The doctors also felt the pressure of service expectations on what they could offer in the time available during the feedback meeting and how this may conflict with what the patient needed in a particular moment.

*“There are so many things one would want to talk with patients about. I know I don’t have time enough to do it, the way that my clinic is structured, to just sit and listen. Let alone my agenda of what I might want to talk about being lasting powers of attorney, wills, you know.” – P10*

The doctors were also aware that a patient and family’s understanding of the diagnosis developed over time, and that questions will arise after the initial feedback appointment. They highlighted the need for families to have opportunities to meet with health care professionals after the diagnosis was initially delivered.

*“We actually see people a couple of months later and that’s the point at which we try and see people to discuss other things. Because the first, that first feedback is, you know, people sometimes just don’t ask anything, they can’t imagine what to ask.” – P13*

The doctors expressed a sense of ownership and responsibility for the patients, despite service structures tending to accommodate only diagnostic feedback and brief period of follow up. Even in the settings where some post-diagnostic counseling was available within the service, doctors often advised patients they could contact them personally in the time between feedback appointment and their next follow up. In other services the post-diagnostic follow up was provided solely by third-sector organisations, such as the Alzheimer’s’ society.

*“I hate it when I see people who are going back to (another area). For me, there’s something much easier about encouraging somebody to have medication, or being more supportive if I know that I’m the one that will be following up.” – P5*

### *Balancing personalisation and flexibility with institutional agendas*

Providing a personalised and flexible approach for each patient was challenged by the ‘institutional’ agenda and memory clinics pathways often not encouraging further medical appointments. Doctors in services with robust follow up felt more comfortable leaving sensitive and complex topics for another day.

*“What I’ve taken away (from training), is preparing to see your agenda going out the window, and I’m much more relaxed now. Sometimes it’s really not possible, and it will make the situation much worse if you try to get all the information into one session.” – P14*

Many services promoted Advance Care Planning (ACP) which included consideration of advance statements, decisions to refuse treatment and Lasting Power of Attorney (LPA) (NICE, 2016). Doctors agreed that early ACP discussions were important whilst patients retained capacity but the most suitable timing of these conversations was less clear.

*“It (ACP) should be sort of in that sort of first 6 months that follow the diagnosis, and preferably by somebody that the patient and family members are comfortable with.” – P13*

## Discussion

This study explored doctors’ perspectives on making and delivering diagnoses in memory clinics. Governmental drives to boost diagnosis rates were mostly viewed positively in terms of people with dementia and their relatives accessing support and information. However, limited post-diagnostic follow-up created concern. Doctors felt expectations from commissioners, alongside cuts to post-diagnostic support and social services placed memory clinics, doctors, patients and families in a difficult position. Such concerns have been expressed repeatedly by various clinical groups who feel service models focusing solely on diagnosis, with swift discharge to primary care are unsatisfactory (British Psychological Society, 2014; Evans, 2014).

Explicitly naming ‘dementia’ was described as being a vital part of feedback; suggesting a possible shift in practice from previous research which demonstrated avoidance of clear diagnostic terms (Dooley et al., 2015; Kissel & Carpenter, 2007; Peel, 2015; Phillips et al., 2012). A small study conducted in UK memory clinics in 2012 found doctors usually avoided the word ‘dementia’ (Peel, 2015). However, a more recent video observation of diagnostic feedback meetings 2014-2016 found that dementia was always named (Dooley et al., 2018).

However, the doctors described strategic and individualised use of ‘dementia’ and ‘Alzheimer’s’ labels. Timing and placement of these terms was linked with the challenge of continuity and personalisation. Those doctors meeting patients for the first time in feedback needed to gauge patient expectations prior to diagnosis delivery. The importance of patient preparation for diagnosis echoes the concept of diagnosis as a ‘journey’ or a cumulative process (British Psychological Society, 2014; Dhedhi et al., 2014).

The delicate balance between instilling hope and communicating clear diagnostic and prognostic information has been described frequently in other bad news consultations (Begley & Blackwood, 2000; Del Vento et al., 2009). The doctors emphasised helpful aspects of receiving a diagnosis; such as increased support and access to medication. However, they expressed a wariness of positivity in potentially contributing to patient confusion about the seriousness of the condition. Research in cancer consultations found individuals hearing positively framed prognoses had reduced distress, but recalled prognostic statistics less accurately (Porensky & Carpenter, 2016). There is even more potential for such misunderstandings in memory clinics, where patients have cognitive impairment.

The abstract nature of the information to be communicated must also be considered. MCI was identified as bewildering for both doctors and patients, partly due to the controversy and lack of clarity around its existence as a diagnostic entity, and its uncertain prognosis. Recent literature highlighted that MCI remains a diagnostic cohort which is pathologically, clinically and prognostically heterogeneous (Cooper, Sommerlad, Lyketsos, & Livingston, 2015).

Doctors wished to provide continuity of personalized care. They described tailoring a narrative for diagnosis and being flexible and sensitive in treatment and prognostic discussions. This approach echoes evidence in oncology where metasynthesis of breaking bad news studies suggested clinicians are balancing the individual relationship with their patient, systemic environment and the cultural milieu (Bousquet et al., 2015). The authors suggest personalization and avoiding generic approaches are key in developing high level communication skills (Bousquet et al., 2015). The structures and pressures on memory clinics in the UK mean that clinicians face an even greater challenge in providing this ideal patient-centred care.

A key motivation for early diagnosis is the opportunity to plan for the future (Holt, 2011). NICE (National Institute for Health and Care Excellence) guidelines recommend advance care planning for patients with dementia early in the illness (NICE, 2016). Doctors felt diagnostic feedback sessions were not the appropriate setting to discuss advanced care planning, which is consistent with patient preferences (Dickinson et al., 2013). Barriers to these conversations include lack of knowledge and awareness, and finding the right time (Dickinson et al., 2013). The doctors reiterated these challenges – that a suitable time, place and process of within existing systems is difficult. In services where patients are discharged to primary care quickly after diagnosis, the opportunity for making such decisions and having conversations could easily be lost.

Decisions in feedback appointments were identified as commencement of medication, psychological treatments, and driving. Meeting for the first time and limited follow-up appointments with the same clinician presented challenges. The doctors felt genuine shared decision making required comprehensive understanding of individuals and their situation, with time for exploration and deliberation. This is particularly important given that doctors and relatives appear to be poor at predicting preferences of patients with dementia for participation in decision making (Hamann et al., 2011). Therefore it is vital to allow professionals involved in such decisions time to understand and know patients if they are to benefit from early diagnosis.

The triadic nature of feedback consultations adds further layers of complexity to communication. While observational studies showed triadic feedback interactions tend towards a series of dyads, often with patient marginalization (Karnieli-Miller et al., 2012), these doctors described more nuanced management of the interaction. Companions were seen as a resource and ally for patients, but also subtly communicating their own burden. Doctors were sensitive to the need to identify cues from both parties and negotiate each

participant's needs. This is consistent with direct observations from a small study in UK memory clinics where the author describes the doctor's multilayered task of communicating complex information as well as responding to unfolding interpersonal dynamics (Peel, 2015).

Doctors described delivering dementia diagnoses as emotionally demanding with limited access to supervision. Few had received training specific to breaking bad news in dementia. Many used strategies taught medical school including checking expectations, prior knowledge, and asking permission (Baile et al., 2000; Kaye, 1997). However, the complicated diagnostic information to be communicated in memory clinics creates specific challenges. Therefore, training and peer support for doctors working in memory clinics will be vital in fostering high quality care and communication and to prevent burnout and emotional disengagement. Researchers looking at the delivery of cancer diagnosis argue that focusing on responding to patient displays of emotion represent an 'empathic opportunity' (Maynard & Frankel, 2006). It is suggested that doctors would benefit from training in both self-awareness, and in determining patient's needs and desires for information (Maynard & Frankel, 2006).

Although there is a growing evidence base for communication training for frontline staff working with people with dementia, the tailored education for medical professionals remains limited (Eggenberger, Heimerl, & Bennett, 2013). A recent review has identified that the most efficacious educational programs were relevant to the health care professional's role and experience (Surr et al., 2017). A workshop for old age psychiatrists involving small groups and video role play to practice specific communication skills to foster patient centered care has been piloted (Robinson et al., 2010). Feedback from participants was positive in terms of the doctor's perceived behaviour change, however the workshop has not had widespread availability and evidence of impact on patient experience is lacking (Robinson et al., 2010).

The findings of this study highlight the intricacy of the task of delivering a diagnosis and that further research is needed to identify best practice in this area. The doctor viewpoints emerging from these focus groups emphasized that receiving a diagnosis of dementia is a process, seated within systems, and impacted upon by factors within and outside the consultation.

However, focusing only on diagnosis delivery would be inadequate to encompass the multitude of issues interacting at each stage. Qualitative research from the perspectives of patients and their families has much to offer in this regard. It is hoped that continued analysis of ShareD study data will allow triangulated observations of patient, companion and doctor experience to identify the impact of particular approaches, and clarify some points of good practice which can be communicated to both clinicians and commissioners.

## **Strengths and Limitations**

This study captured the views of a range of frontline doctors from different specialties, delivering dementia diagnoses in a range of memory clinics. Half of

the data were jointly analysed by at least two authors increasing validity. The inter-rater reliability on 31% of the data was high.

The doctors were participating in the ShareD study and perhaps more likely to reflect on their approach to diagnosis. Two of the focus groups contained specialist registrars and their consultants which may limit free expression. Whilst the majority of these doctors described meeting patients for the first time in feedback this may not be representative of all memory clinics.

## **Conclusions:**

Delivering a dementia diagnosis is a nuanced and challenging task. Balancing honest description of a life limiting condition whilst instilling hope is further complicated when cognitive impairment affects comprehension. Clear and considerate communication is important as misunderstandings in these consultations may limit patient opportunities for informed future planning afforded by early diagnosis. Existing breaking bad news frameworks do not easily apply. Feedback consultations are often triadic; including patients and companions who may have conflicting needs, insight and expectations. Deciding what can be discussed in front of both parties requires a delicate approach. These challenges are further exacerbated by concerns about lack of continuity and inadequate post-diagnostic care. Doctors in memory clinics would benefit from evidence based training and supervision to prepare them for these emotionally challenging and complex consultations.

## References:

- Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist*, 5(4), 302-311. doi:10.1634/theoncologist.5-4-302
- Begley, A., & Blackwood, B. (2000). Truth-telling versus hope: A dilemma in practice. *International Journal of Nursing Practice*, 6(1), 26-31.
- Blair, M., Marczyński, C. A., Davis-Faroque, N., & Kertesz, A. (2007). A longitudinal study of language decline in Alzheimer's disease and frontotemporal dementia. *J Int Neuropsychol Soc*, 13(2), 237-245. doi:10.1017/s1355617707070269
- Bousquet, G., Orri, M., Winterman, S., Brugiere, C., Verneuil, L., & Revah-Levy, A. (2015). Breaking Bad News in Oncology: A Metasynthesis. *J Clin Oncol*, 33(22), 2437-2443. doi:10.1200/JCO.2014.59.6759
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- British Psychological Society. (2014). *Clinical Psychology in the Early Stage Dementia Care Pathway*. Retrieved from London, England:
- Cooper, C., Sommerlad, A., Lyketsos, C. G., & Livingston, G. (2015). Modifiable predictors of dementia in mild cognitive impairment: a systematic review and meta-analysis. *Am J Psychiatry*, 172(4), 323-334. doi:10.1176/appi.ajp.2014.14070878
- Del Vento, A., Bavelas, J., Healing, S., MacLean, G., & Kirk, P. (2009). An experimental investigation of the dilemma of delivering bad news. *Patient Educ Couns*, 77(3), 443-449. doi:10.1016/j.pec.2009.09.014
- Department of Health. (2016). *Prime Minister's Challenge on Dementia 2020: Implementation Plan*. Retrieved from gov.uk: <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>
- Dhedhi, S. A., Swinglehurst, D., & Russell, J. (2014). 'Timely' diagnosis of dementia: what does it mean? A narrative analysis of GPs' accounts. *BMJ Open*, 4(3), e004439. doi:10.1136/bmjopen-2013-004439
- Dickinson, C., Bamford, C., Exley, C., Emmett, C., Hughes, J., & Robinson, L. (2013). Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr*, 25(12), 2011-2021. doi:10.1017/S1041610213001531
- Dooley, J., Bailey, C., & McCabe, R. (2015). Communication in healthcare interactions in dementia: a systematic review of observational studies. *Int Psychogeriatr*, 27(8), 1277-1300. doi:10.1017/S1041610214002890
- Dooley, J., Bass, N., & McCabe, R. (2018). How do doctors deliver a diagnosis of dementia in memory clinics? . *BJPsych*, In press.
- Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatr*, 25(3), 345-358. doi:10.1017/S1041610212001664
- Evans, S. (2014). What the National Dementia Strategy forgot: providing dementia care from a psychodynamic perspective. *Psychoanalytic Psychotherapy*, 28(3), 321-329. doi:10.1080/02668734.2014.937943

- Hamann, J., Bronner, K., Margull, J., Mendel, R., Diehl-Schmid, J., Buhner, M., . . . Pernecky, R. (2011). Patient participation in medical and social decisions in Alzheimer's disease. *J Am Geriatr Soc*, *59*(11), 2045-2052. doi:10.1111/j.1532-5415.2011.03661.x
- Hansen, E. C., Hughes, C., Routley, G., & Robinson, A. L. (2008). General practitioners' experiences and understandings of diagnosing dementia: factors impacting on early diagnosis. *Soc Sci Med*, *67*(11), 1776-1783. doi:10.1016/j.socscimed.2008.09.020
- Hellstrom, I., & Torres, S. (2013). A wish to know but not always tell -- couples living with dementia talk about disclosure preferences. *Aging Ment Health*, *17*(2), 157-167. doi:10.1080/13607863.2012.742491
- Holloway, R., Gramling, R., & Kelly, A. (2013). Estimating and communicating prognosis in advanced neurologic disease. *Neurology*, *80*, 764-772.
- Holt, G. R. (2011). Timely diagnosis and disclosure of Alzheimer disease gives patients opportunities to make choices. *South Med J*, *104*(12), 779-780. doi:10.1097/SMJ.0b013e3182389599
- Huberman, A., ; Miles, M. (1994). Data Management and Analysis Methods. In N. Denzin, ; Lincoln, Y (Ed.), *Handbook of Qualitative Research* (Vol. 1). Thousand Oaks, CA: SAGE.
- Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., & Eidelman, S. (2007). Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: walking an ethical and professional tight rope. *Patient Educ Couns*, *67*(3), 307-314. doi:10.1016/j.pec.2007.03.014
- Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. *Int Psychogeriatr*, *24*(11), 1756-1770. doi:10.1017/S1041610212000841
- Kaye, P. (1997). *Breaking Bad News: A 10 Step Approach* (1 ed. Vol. 1). Northampton: EPL.
- Kissel, E. C., & Carpenter, B. D. (2007). It's all in the details: Physician variability in disclosing a dementia diagnosis. *Aging and Mental Health*, *11*(3), 273-280.
- Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., . . . Drummond, N. (2011). Pathways to diagnosis: exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health Soc Care Community*, *19*(4), 372-381. doi:10.1111/j.1365-2524.2010.00982.x
- Lindesay, J., Marudkar, M., van Diepen, E., & Wilcock, G. (2002). The second Leicester survey of memory clinics in the British Isles. *Int J Geriatr Psychiatry*, *17*(1), 41-47.
- Maynard, D., & Frankel, R. (2006). On diagnostic rationality: Bad news, good news, and the symptom residue In J. H. D. W. Maynard (Ed.), *Communication in medical care* (Vol. 1, pp. 248-278). New York, NY: Cambridge University Press.
- NICE. (2016). Dementia: supporting people with dementia and their carers in health and social care *CG42*. England: NICE.
- Peel, E. (2015). Diagnostic communication in the memory clinic: a conversation analytic perspective. *Aging Ment Health*, *19*(12), 1123-1130. doi:10.1080/13607863.2014.1003289

- Phillips, J., Pond, C. D., Paterson, N. E., Howell, C., Shell, A., Stocks, N. P., . . . Marley, J. E. (2012). Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *The British Journal of General Practice*, 62(601), e546-e553. doi:10.3399/bjgp12X653598
- Porensky, E. K., & Carpenter, B. D. (2016). Breaking bad news: Effects of forecasting diagnosis and framing prognosis. *Patient Educ Couns*, 99(1), 68-76. doi:10.1016/j.pec.2015.07.022
- Quinn, C., Clare, L., Pearce, A., & van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: an interpretative phenomenological analysis. *Ageing Ment Health*, 12(6), 769-778. doi:10.1080/13607860802380623
- RCPsych. (2016). *Memory Services National Accreditation Program (MSNAP): Standards for Memory Services*. Retrieved from London, England: [http://www.rcpsych.ac.uk/pdf/MSNAP\\_standards\\_5th\\_edition.pdf](http://www.rcpsych.ac.uk/pdf/MSNAP_standards_5th_edition.pdf)
- Robinson, L., Bamford, C., Briel, R., Spencer, J., & Whitty, P. (2010). Improving patient-centered care for people with dementia in medical encounters: an educational intervention for old age psychiatrists. *Int Psychogeriatr*, 22(1), 129-138. doi:10.1017/S1041610209990482
- Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., . . . Dennison, A. (2017). Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature. *Rev Educ Res*, 87(5), 966-1002. doi:10.3102/0034654317723305