

# **Communicating a Diagnosis of Dementia**

Submitted by Jemima Mary Beatrice Dooley to the University of Exeter as a thesis for the degree of Doctor of Philosophy in Medical Studies, November 2016.

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## Abstract

*Background:* There has been a rise in dementia awareness, with policy changes leading to increased diagnosis rates. However, the stigma of dementia is likely to cause challenges in diagnostic communication. This is complicated by the effect of dementia on cognitive functioning. The aims of this study were to (1) identify how diagnoses of dementia are communicated, (2) identify how people with dementia respond to the diagnosis, and (3) explore doctors' perspectives on dementia diagnosis delivery.

*Methodology:* A systematic literature review was conducted. Twenty doctors from 9 memory clinics across 4 NHS trusts participated. Eighty-one dementia diagnosis feedback meetings were video-recorded. Conversation analysis was used to identify patterns in diagnosis delivery. Four focus groups with the participating doctors were analysed using thematic analysis (inter-rater reliability 0.89).

*Findings:* The literature review highlighted the dilemma of communicating both sensitively and honestly with people with dementia, as well as challenges stemming from cognitive impairment. This was also evident in diagnostic communication. Prior to diagnosis doctors elicited patient orientation to the meeting purpose (*"do you know why you're here?"*) and perspective into symptoms (*"how is your memory?"*). The majority of patients displayed some confusion as to the meeting purpose and offered non-medicalised explanations for their symptoms. Doctors attempted to address this through repeated explication of test results and statements of the clinic purpose. Dementia was always explicitly named. Diagnoses were often delivered indirectly (*"that is dementia"*), a practice to manage patient resistance and negative responses. However, over 40% were delivered directly (*"you have dementia"*), especially when patients were more cognitively impaired. Doctors pursued non-minimal responses to diagnosis, apparently to obtain perspective before progressing to treatment. However, resistance was not always addressed and prognosis was often avoided. Doctors highlighted pressure to make diagnoses and an aim to emphasise *"living well"* rather than discussing prognosis.

*Conclusion:* The findings of this study highlighted the delicate balance between minimising likely resistance and distress and maximising understanding in the context of cognitive impairment. Instilling hope is evidently a priority for doctors. The diagnosis meeting is just one part of the journey of the person with dementia, and sufficient pre- and post-diagnosis support is integral.



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## **Statement of Involvement in the ShareD Study**

The data for this thesis was collected as part of the Shared Decision Making in Mild to Moderate Dementia (ShareD) study. I was involved with project management duties on ShareD from its inception and throughout my PhD. This included assisting with writing and costing the grant application, developing the protocol, outcome measures and topic guides, submitting the ethics application and 4 subsequent amendments, and the recruitment of participants. I led on the study set-up and recruitment of professionals for 6 months. When the researchers began in post I familiarised them with the protocol, introduced them to memory clinic teams, recruited professionals and patients, recorded meetings and administered questionnaires. I initially took the lead in project management, and assisted in the set up of data records and storage systems, as well as the SPSS database. When the study was past set up stage I took a less active role. After this point, I attended 18 clinics, recruiting 4 professionals and 8 patients, and conducting 5 follow-up interviews. Additionally, I transcribed 9 full meetings. Throughout the first 18 months of my PhD I attended bimonthly study meetings in London, weekly teleconferences, and weekly meetings with the ShareD Devon team.

The focus groups, which are analysed in Chapter Seven, were conducted as part of the ShareD study. I was a key part of the research team at every step of the focus group organisation, and took a lead role in developing the topic guide and liaising with the Alzheimer's Society research network for its review. I was present at one focus group. I took part in regular 2-hour meetings from December 2015-September 2016 on the analysis of the transcripts, particularly the data reduction and conceptualizing the categories, subthemes and themes, and the write up of a paper on the results. I am second author on the paper of the focus group study, which is soon to be submitted for publication.

### **A note on Terminology**

People with dementia will be referred to as 'patients' throughout the thesis. It is important for people with dementia not to be classified by their condition.

However, the data presented is in the form of doctor-patient interaction, and the person with dementia inhabits the role of the patient within this context. The term 'companion' will be used for the family member, friend, or other person accompanying the patient to the memory clinic.

# **Chapter One: Introduction**

## Background

Dementia encapsulates a set of symptoms indicating a decline in cognitive functioning, which can be caused by numerous progressive conditions. Common symptoms include impairments in memory, attention, concentration, language, and spatial and temporal perception, but the symptom profile can vary widely between different types of dementia and different individuals. There are an estimated 35.6 million people living with dementia worldwide, with 7.7 million people developing the condition every year. One in 6 adults over the age of 80 in the UK have dementia (Alzheimer's Society, 2013).

Dementia awareness has increased dramatically over the past two decades. In the 20<sup>th</sup> and early 21<sup>st</sup> Century the common view was that disclosing a dementia diagnosis was futile given that the condition causes people to forget information and that there is no effective treatment or cure (Pinner, 2000). However, a diagnosis of dementia is being recognised as increasingly important in order to develop interventions and treatment. Across the world there have been changes in healthcare policy regarding dementia, with a focus on identifying dementia in the earlier stages (World Health Organisation, 2012, Alzheimer Europe, 2016, Department of Health, 2009). The UK government, in line with the Alzheimer's Society Right to Know campaign, are pushing for higher rates of diagnosis at earlier stages of the illness (Department of Health, 2009, Alzheimer's Society, 2013). There is an emphasis on 'timely' diagnoses – a person-centred approach where people receive a diagnosis at the time that is best for them (Dhedhi et al., 2014). The result of this increase in awareness is that UK dementia assessment attendance has increased by 40% in 4 years, and diagnosis rates have risen by 17% between 2010 and 2015 (Parkin and Baker, 2015).

However, there are currently no disease-modifying treatments and limited psychosocial support for people with dementia. This rapid rise in dementia diagnosis and awareness has thus led to some concern that a focus on diagnosis without similar improvements in treatment and support will lead to increased pressure on services and may lead to distress to people with dementia and their families (Robinson et al., 2015). There is a suggestion that

while diagnosis is useful for signposting to services, receiving an official diagnosis may not be as important for people with dementia, and may lead to lower mood (Clare et al., 2016).

Although there has been an increase in dementia diagnosis, it is currently an under-researched area. Patterns in how patients seek help for the early symptoms of dementia have been explored. People first notice a variety of different symptoms, which is described in a study by Leung et al as behaviours that are “inconsistent with how they ‘used to be’” (Leung et al., 2011, p376). People may attribute their cognitive difficulties to old age and families can be the instigator in approaching medical professionals (Perry Young et al., 2016). Similarly, people’s experiences of diagnosis and treatment have been reported, with patients and their families often feeling a lack of support after they have received a diagnosis (Samsi et al., 2014). However, there are very few studies of how clinicians tell people they have dementia, or of how patients and their families respond within the diagnosis feedback meeting (Peel, 2015, Dooley et al., 2015).

Delivering diagnoses of life-changing conditions such as dementia has been identified as one of the primary causes of stress and anxiety in medical professionals (Fallowfield and Jenkins, 2004). Although there has been an increase in training interventions for the delivery of physical health diagnoses, particularly in oncology (e.g. Kaplan, 2010), there are far fewer studies aimed at improving communication of mental health diagnoses, and healthcare professionals receive very little guidance as to how this should be done (Milton and Mullan, 2014). Diagnoses of dementia will cause additional difficulties, as many communication techniques that are recommended in breaking bad news training, such as preparing the patient and delivering the news in small amounts of information, will be more difficult with patients with impaired short term memory, attention, and concentration (Tuffrey-Wijne, 2013).

The topic of this thesis is how a diagnosis of dementia is communicated in specialist settings in the UK. This will include how clinicians approach the diagnosis, name and explain dementia as a condition, and how people with dementia respond to the diagnosis. This chapter will set the context of the

research, beginning with a short description of dementia and the memory clinic set-up, where the majority of people are assessed for possible dementia in the UK. The second section will be an overview of observational studies exploring diagnosis deliveries in other medical settings, which will illustrate how diagnostic interactions typically unfold.

## **Dementia and Memory Clinics**

### *What is Dementia?*

Dementia is an umbrella term for a number of irreversible degenerative conditions. The type of dementia is determined by the cause, and this will affect the trajectory and to some extent the symptoms experienced by a person with dementia. Dementia can cause a decline in memory, the ability to learn new information, reasoning and visuospatial skills, concentration, orientation, and communication (World Health Organisation, 1992). The reduction in cognitive processing that comes with dementia causes difficulties in conducting everyday tasks and interacting with others, leading to a reduction in a person's ability to live independently and changes in personality (Barbas and Wilde, 2001, Jacomb and Jorm, 1996).

The type of dementia is determined by the cause, and this will affect the trajectory and to some extent the symptoms experienced by a person with dementia (Knapp and Prince, 2007). Alzheimer's disease is the most common cause of dementia, and is caused by the build up of proteins in the brain forming plaques that lead to the loss of brain tissue. Vascular dementia is the second most common form and is caused by a lack of blood supply in the brain, most commonly a product of small strokes. Alzheimer's disease is characterised by a smooth, gradual decline in cognitive abilities, while with vascular dementia the symptoms are more likely to stay constant for a time and then suddenly deteriorate in a step-wise fashion. Alzheimer's disease generally starts with memory difficulties, accompanied by problems with language and orientation. Vascular dementia may not start with the memory difficulties and its symptoms involve problems with processing speed and concentration, as well as changes in behaviour and other symptoms of stroke. People often have pathologies of

both Alzheimer's disease and Vascular dementia, and diagnoses of mixed dementia are common (Zekry et al., 2002).

There are numerous other, more rare, types of dementia. Frontotemporal dementia is a dementia subtype characterised by symptoms of frontal lobe damage. It is usually sub-divided into behavioural variant frontotemporal dementia, involving changes in personality and behaviour, and semantic dementia, which involves the gradual loss of conceptual knowledge. Other dementia types include dementia with Lewy bodies, where memory problems and disorientation are commonly accompanied by hallucinations, and Korsakoff's syndrome, which is usually associated with heavy alcohol use. Progressive neurological conditions such as Parkinson's disease and Huntington's disease are also strongly associated with dementia. For example, studies show that up to 36% of people newly diagnosed with Parkinson's disease will have cognitive decline and 75% of people who have Parkinson's for over 10 years developing dementia (Meireles and Massano, 2012).

The symptom profile and prognosis of dementia are affected by age of onset. For example, frontotemporal dementia is much more likely in people with dementia under the age of 65, while dementia with Lewy Bodies is more common in older people with dementia (Sampson, 2004). People with young-onset dementia are more likely to be assessed and diagnosed in neurology settings rather than memory clinics (National Institute for Clinical Excellence, 2006). Additionally, for people over 65 with dementia diagnoses, those who received the diagnosis at a younger age tend to live longer (Xie et al., 2008).

Other diagnoses made in memory clinics include Mild Cognitive Impairment (MCI), which is characterised by a decline in cognitive function beyond that of typical ageing, but not affecting the person's life to the extent of fulfilling the criteria of dementia (Petersen, 2011). Additionally, people can be diagnosed with Subjective Cognitive Decline (SCD), defined by personal reports of memory impairments with no sign of difficulties on cognitive tests (Blackburn et al., 2014). Symptoms of psychological conditions such as anxiety or depression can also manifest themselves in cognitive difficulties and can be confused with dementia. Additionally, mild forgetfulness can be a normal part of ageing.

Therefore, when doctors are making dementia diagnoses, they will need to decide whether the patient's memory problems are causing difficulties over and above one of these conditions. This decision is a clinical one, in that there is no one test for dementia, and thus it can be difficult to make in the early stages of the condition. Often, what will differentiate dementia from other problems of cognitive functioning is evidence of deterioration over time.

If a person is concerned about their memory in the UK they are often referred to a memory clinic, in order to be assessed and potentially receive a diagnosis dementia.

### *The development of Memory Clinics in the UK*

Memory clinics consist of multidisciplinary teams who assess and diagnose dementia, and provide medication and psychosocial support (Hodge and Haley, 2013). Memory clinics were first established in the UK in the 1980s and much of their early focus was on research, largely around medication (Moniz-Cook and Woods, 1997). It was not until 1997, with the introduction of cholinesterase inhibitors as a specific treatment for dementia, that services began to be developed nationwide (Lindesay et al., 2002). Dementia care remained sporadic and varied greatly according to region, and it was only in 2001 that the Department of Health specified that older adult mental health services “*should include memory clinics*” as a centre for dementia assessment and support (Department of Health, 2001). The development of memory clinics has increased rapidly since then, with standardisation of high quality care bring a primary focus, for example with the development of the Memory Services National Accreditation Programme in 2009 (Hodge et al., 2014).

The increased number of memory clinics coincided with an increased awareness of the prevalence and cost of dementia in society, leading to the ‘National Dementia Strategy’ in 2009 (Department of Health, 2009), the ‘Dementia Challenge’ in 2012 (Department of Health, 2012), and more recently the ‘Challenge on Dementia 2020’ (Department of Health, 2015) – all government led initiatives to improve the quality of services for and research into dementia. Early diagnosis was identified as a key target for these strategies, with the aim being that earlier treatment and increased



understanding will lead to more patient centred care, with higher patient involvement in future planning in the earlier stages in the illness meaning less responsibility on family members as the illness progresses (Holt, 2011).

Memory clinics are regarded as having an important role in fulfilling this aim, both as the point of referral for other services and in providing education and counselling for patients and their companions (Passmore and Craig, 2004).

### *The Memory Clinic Process*

Memory clinic attendance has increased four-fold since 2010. A 2014 audit of 82% of the memory clinics in England found that a memory clinic assesses an average of 18 patients a week, ranging widely from 2 to 102 (Hodge and Hailey, 2015). The average time from when people with dementia and their families notice something is amiss to a formal diagnosis is just under three years (Chrisp et al., 2011). Once people have been referred to a memory clinic the process from assessment to diagnosis takes on average 8.5 weeks, but can be up to 40 weeks (Hodge and Hailey, 2015). Memory clinics are usually placed in secondary care. People with suspected memory problems are referred from their GP after physical testing, which include blood tests and also urine tests and heart examinations if needed. Within memory clinics, patients will undergo a CT scan of the brain, a detailed discussion of their symptom history, and cognitive assessment. The cognitive assessments that are used vary, with the most common being the Addenbrooke's Cognitive Evaluation (ACE-III) (Mioshi et al., 2006) and the Mini Mental State Examination (MMSE) (Folstein et al., 1983). These tests generally take between 30 minutes and an hour. Further physical and neuropsychological testing will happen as required, primarily in mild or questionable cases (National Institute for Clinical Excellence, 2006). There is no one test for dementia: neither the brain scan nor the cognitive test results can give a definitive dementia diagnosis, but clinicians in memory clinics use a combination of all the information gathered to come to a clinical judgement.

Memory clinics vary in how they operate, but are most frequently run by psychiatrists, neurologists or geriatricians, alongside psychologists, nurses, and occupational therapists (Passmore and Craig, 2004). Once diagnosis has been established, treatments that memory clinics can offer are threefold: (1)

medication, with cholinesterase inhibitors, antipsychotics, and antidepressants being most commonly prescribed; (2) psychological treatments, such as cognitive stimulation, validation therapy, and life story work; and (3) education for people with dementia and their families, such as carer support groups. The cholinesterase inhibitors (along with memantine, which works to control excess glutamate levels and is more commonly described in later dementia) are the only available medication for dementia-specific symptoms. However, these are only available for some types of dementia, primarily Alzheimer's disease. Additionally, while these medications can provide some symptom improvement, they do not work for all people and do not stop the eventual progression of dementia (Trinh et al., 2003). Memory clinics will also refer patients and their families to social services or other charitable networks for additional support if necessary. Additionally, there is a wide variation in the extent to which psychosocial and education-based treatments are provided throughout the UK.

#### *Communication of dementia diagnoses in Memory Clinics*

Few studies have directly observed communication in memory clinics, and those that have will be discussed in detail in the systematic literature review in Chapter 2. However, research exploring how clinicians and people with dementia and their families experience delivering and receiving dementia diagnoses show complexities and challenges beyond that of other conditions.

While in most medical conditions the patient can be taken as an expert on their symptoms, with dementia one's ability to both remember and recognise a change in one's own behaviour may be affected. Patients may not remember instances where they have forgotten things, or may have forgotten why and/or how they are at the clinic at all. This is exacerbated by the fact that many people attend memory clinics because of concerns raised by their families or friends rather than symptoms they have noticed themselves (Quinn et al., 2016, Karnieli-Miller, 2012). Therefore, the patient's lack of involvement in the help-seeking process means they can be disorientated about the purpose of the diagnostic meeting.

In addition to memory difficulties, many people with dementia may demonstrate different levels of awareness of their symptoms when talking to families, friends,

and healthcare professionals. Clare and colleagues (2008, p2367) define awareness as “*a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications*”. Awareness is a complex construct, with the literature containing heterogeneous terminology, measures, and contexts (Marková et al., 2005). In memory clinic diagnostic interactions, awareness should generally be considered in the context of patients’ “evaluative judgements” of behavioural changes (Clare et al., 2011), rather than manifestations of neurological symptoms. Patients in memory clinic assessments and diagnosis are asked to compare current abilities to past abilities (e.g. with remembering names, or driving), or assess internal mental states (e.g. mood or personality changes). These judgements may be affected by people’s ability to monitor their performance on day-to-day tasks, which may be caused by neurological changes (McGlynn and Schacter, 1989). However, the delicate and dispreferred nature of making negative public judgement of one’s own abilities means this is more likely to be affected by social and psychological factors, such as embarrassment, frustration, distress, or a self-maintaining coping style (Clare et al., 2013, Clare et al., 2012, Howorth and Saper, 2003, Mograbi et al., 2012). Dementia is a stigmatised mental illness, and patients may therefore not want to discuss symptoms publically, resisting doctor questions and assessments (Milne, 2010). Furthermore, awareness will manifest differently according to what aspect of the person’s behaviour is being discussed – for example people may discuss their memory problems but not problems with other aspects of functioning such as the ability to live independently (Marková et al., 2014). As Clare et al (2011, p941) state “*difficulties with evaluative judgements at this level become evident when the beliefs or concepts expressed are clearly discrepant with the objectively observed situation*”. If people’s reports of their symptoms differ to those of their companions, or what has been demonstrated on the cognitive testing, this can cause challenges for diagnostic communication.

Additionally, as with all people who are referred to secondary care services for assessment for potentially serious conditions, people attending memory clinics will be experiencing anxiety and concern for their future (Aminzadeh et al., 2007). Dementia is one of the biggest fears of older adults (Bond and Corner,

2001), and is associated with disability and loss of independence (Milne, 2010). Many people will know or have known loved ones with dementia, and thus attendance at the memory clinic may cause anxiety about their own future (Kinzer and Suhr, 2016). Therefore, it is not surprising that fear of causing trauma to the patient is one of the main concerns for clinicians in memory clinics (Johnson et al., 2000), which has been reported to cause qualified and unclear communication of diagnostic information (Karnieli-Miller, 2007).

Another complication is that, although in current practice disclosure is encouraged and does occur (McKinlay et al., 2014), the difficulty in disentangling early signs of dementia with normal ageing or other causes can lead to incorrect diagnoses being delivered. Clinicians have identified the uncertainty in coming to a diagnosis decision – with the need to look at the culmination of evidence from the history, scan, and cognitive test, rather than there being one clear test – as a reason for reluctance about telling people they have dementia (Carpenter and Dave, 2004). Uncertainty is likely to be higher given the rapid increase in memory clinic attendance in the last 4 years, with increasing numbers of people in the early stages of the illness receiving a diagnosis (Brunet, 2014). Additionally, the memory clinic model of assessment and feedback occurring in secondary care (as described in detail in Chapter 3), does not easily allow for repeated assessment over time, which can be helpful in reaching a firm diagnosis in the early stages of dementia.

Despite these challenges, the current guidance for clinicians in delivering a dementia diagnosis is scarce. The National Institute of Clinical Excellence (NICE) guidelines for dementia services in the NHS have not been updated since 2006 (a new version is due for release in June 2018). They provide little detail on the communication of the diagnosis other than *“healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members”* (National Institute for Clinical Excellence, 2006, :23). The Memory Services National Accreditation Programme (MSNAP) have published standards for memory clinics to work towards, but again have little detail on the communication of the diagnosis other than *“the outcome of the assessment is communicated to all relevant parties in a timely manner”* (Hodge et al., 2014,

:31). The British Psychological Society (Murphy and Gair, 2016) have noted the gap in guidance for clinicians, and have published their own advice in a 4 step model: preparation and understanding of information, provision of information, service provision of treatment and support, and provision of time to accommodate to the nature of the diagnostic process. Their guidance is more specific, including *“adapt to the patient’s use of vocabulary, comprehension, and processing speed”*, *“subject to person’s preference, social and cultural issues, name the diagnosis explicitly, do not avoid the words”*, *“check for understanding, encourage and answer questions”*, and to *“acknowledge emotions during the session”* (page 14). They also emphasise the importance of focussing on *“identifying remaining abilities”* and *“strategies to live well”*. However, the authors do not offer further guidance in terms of specific communication practices to achieve these goals, given the potential challenges outlined above. While a timely diagnosis will depend on the individual and thus cannot be dictated by an overarching guidance, there is no advice given on how to assess timeliness of diagnosis on a patient-by-patient basis.

This thesis involves microanalysis of video recorded communication of a diagnosis of dementia in memory clinics. The primary method to examine the diagnosis delivery will be conversation analysis (CA).

### **Conversation Analysis and Diagnosis Delivery**

The use of conversation analysis (CA) to examine medical interactions grew from pioneering studies in the seventies and eighties examining the asymmetrical doctor-patient relationship (Beckman and Frankel, 1984, Byrne and Long, 1976). The central ethos in medical sociology was that of medical authority – the doctor is the expert in doctor-patient interactions, and therefore dominates discussions in both content and outcome. The structure of diagnostic medical consultations – problem presentation, examination, diagnosis, and treatment – is taught to doctors in medical school. Doctors are thus focused on steering discussions through these stages, often within the time pressures of busy clinics. The main concern of studies in this period was that doctor orientation to this medical agenda, alongside doctor interactional dominance as medical experts, curtails patient involvement in treatment discussions.

However, CA studies have shown that patients are not as passive in medical interactions as first supposed (Drew et al., 2001, Heath, 1992). While doctors are medical experts, patients are experts in their own experience, and will have a specific agenda when visiting the doctor – be it obtaining certain medication, or getting a leave of absence for work (Drew and Heritage, 1992). Therefore, although the structure of medical interactions being led by doctors means that there are constraints on patient input, when patients are invited to speak by the doctor they will design their responses carefully to achieve their goal for the visit (Heritage and Maynard, 2005, Stivers, 2002). In other words, patients are carefully curating their input in medical consultations, and not just passively adhering to the doctor's authority.

An example of how patient agency manifests in interaction is that, if patients are unsure whether doctors can help them with their problem, they will use narrative formats to present their symptoms. The use of narratives works both to elicit some control of the interaction and demonstrate that patients have tried other methods to solve their problems (Heritage and Robinson, 2006). Doctors have been shown to be oriented to the patient's need to demonstrate information in the problem presentation stage of the meeting, and will negotiate rather than direct the movement to the examination phase – monitoring patient cues that their presentation may be complete (Beach, 1995). Negotiation of doctor role as medical expert and patient role as experiential expert has also been reported in other parts of the medical consultation, for example reporting of the test results (Pomerantz and Rintel, 2004) and discussing treatment options (Stivers, 2005).

In the study of diagnosis delivery, there are several key aspects in communicating the diagnosis that have interested conversation analysts.

### *Diagnosis Delivery and Epistemic Authority*

Early studies of diagnosis argued that the doctor has ultimate epistemic authority – i.e. claim to knowledge (Heritage, 2012) – with respect to diagnosis. Doctors are extensively trained experts in diagnosing symptoms, and therefore this epistemic authority is seen as absolute by both patients and doctors. Byrne and Long (Byrne and Long, 1976) examined two thousand GP interactions and

found that this manifests in diagnostic interactions: in the vast majority of cases doctors announce diagnoses and instruct patients on treatment without requesting patient input. Heath (1992) and Peräkylä (1998) examined diagnosis deliveries in primary care in Britain and Finland respectively, and demonstrated that patients rarely respond extensively to diagnosis – approximately two thirds of patients do not respond extensively to diagnosis delivery in both settings. Additionally, both studies showed that doctors leave a gap for patients to respond, indicating that this asymmetry was not simply doctor-led. That patients withhold responses to diagnosis has been argued to be an illustration of their deference to medical expertise, and an orientation to what really matters to patients, which is not the diagnosis itself but the treatment of their condition (Robinson, 2003a).

However, both Heath and Peräkylä further examined diagnosis deliveries where patients did respond extensively to the diagnosis, and found that the picture was more complicated. Heath demonstrated that the seriousness of the diagnosis and length of the diagnostic utterance were not factors in whether patients responded – but if diagnoses were presented as either uncertain or were in some way incongruent with the patient's viewpoint, this increased the likelihood of patient responses. Peräkylä (2002) built on this, showing that patients are more likely to respond to diagnosis when the evidence is referred to in diagnostic delivery, and doctors appear to use this method to encourage patient extended response. However, doctor epistemic authority is still prevalent: when patients disagree they design their turns so as to not directly challenge the doctor's expertise, for example by suggesting a symptom that is misaligned with the diagnosis rather than rejecting evidence from testing. Even straight agreements are designed as personal perspective rather than fact, and thus portrayed as different and inferior to the doctor's expert opinion (Peräkylä, 2002).

### Diagnosis Delivery and Accountability

Maynard (2004, p57) considers diagnoses as "*clinical assessments*". In asserting a diagnosis doctors are assessing the patient's experience, and thus presuming a knowledge or expertise over what should be the patient's epistemic domain. Doctors therefore have to show accountability for this

presumption – particularly in cases where the diagnosis is misaligned with the patient’s own assessment of their symptoms. Peräkylä demonstrated that while Byrne and Long are correct that doctors often appear to assert their diagnoses without discussing the evidence (e.g. “you have X”), these assertions take place immediately after physical examinations (Peräkylä, 2005). This placement makes the diagnosis the upshot of the doctor’s conclusions of the physical examination, and thus demonstrates a level of accountability. In other words, doctors are accounting for their assertions by making the evidence for the assertion clear to the patient. In cases where there may be temporal distance between the examination and the diagnosis, or where there may be some uncertainty in the examination, doctors will reassert the evidence within the diagnosis itself (e.g. “this shows X, so you must have X”). Therefore, doctors are aware of the patient’s ownership of their symptoms, and take care to explicate their evidence within the diagnosis delivery. In citing the evidence doctors are showing the intersubjective nature of diagnosis deliveries: diagnoses are not solely in the domain of the doctor as originally supposed but co-constructed through patient knowledge of the symptoms and doctor medical knowledge.

### *Diagnosis Delivery and Breaking Bad News*

Many CA examinations of diagnosis deliveries have been in primary care. As patients in primary care are able to choose when they see the doctor, they place importance in demonstrating that they have a legitimate reason to seek help from doctors. Therefore disagreement is most common where doctors tell patients they do not have a diagnosable condition (Stivers, 2005). In other words, while it could be considered that a diagnosis of any illness is bad news, a primary care diagnosis leads to validation of a patient’s concern and most commonly to treatment, and thus is potentially a positive outcome for the patient. Secondary care is different. Secondary care services are specialist services and deal with more complex and usually more serious conditions. The patient in most cases will have been referred by the primary care clinician, and thus do not need to be validated by a diagnosis. A diagnosis from a secondary care service is therefore most commonly ‘bad news’, in that it *“adversely and seriously affects an individual’s view of his or her future”* (Buckman et al., 1998).



Bad news diagnosis deliveries are approached with caution. As Maynard (2003a) describes, participants in interactions display reluctance to impart bad news; in CA terms telling someone bad news is a 'dispreferred' activity. In other words, while good news is forthrightly delivered, bad news deliveries are delayed, shrouded in other information deliveries or presented only as responses to questions, and glossed over with minimisation or positive spins on the news. In clinic settings bad diagnostic news has been shown to be prefaced with modifiers ("*this probably is..*") and litotes ("*it's not good*"), with euphemisms commonly used (e.g. "*condition*" "*tumour*") (Stivers, 1998, Del Vento et al., 2009). Additionally, "*good news exits*" (Maynard, 2003a, :158) from bad news are commonly implemented, with optimistic projections regarding the diagnosis trajectory (e.g. "*it's potentially serious but the majority are cured*") (Leydon, 2008). Maynard argues that it is in doctors' interests to not focus on the 'badness' of the diagnosis so they can minimise responses that will delay the progression to the treatment stage of the meeting. Diagnoses are thus often communicated using factual and abstract wording to encourage a stoic response.

#### *Diagnosis Delivery and Patient Response*

There are 3 main types of patient response to diagnosis discussion: negative responses to diagnosis, resistance to diagnosis, and misunderstanding diagnostic information.

#### *Negative Responses to Diagnosis:*

Maynard argues that the avoidance of the negative aspects of diagnoses in the delivery is why patients generally do not respond to diagnostic news, even in life changing conditions like cancer or HIV. Additionally, bad news tends to be delivered with a low tone of voice, often with falling pitch and slow delivery, which encourages minimal response in a similar tone (Maynard and Freese, 2012). There are few reports of emotional responses to diagnosis. In oncology, doctors rarely ask how the patient feels or leave room for patients to volunteer emotional information. Patients refer inexplicitly to concerns ("*I hope I've caught it early enough*"), but doctors tend to not to pursue them (Beach et al., 2005). Through being the speaker of the diagnostic news, doctors will always have the

first opportunity to provide a “*meaning assessment*” (Maynard, 2006, :1903) – i.e. an indication of the consequences of the news for the patient. Doctors will nearly always use this space to deliver a positive assessment of the news, regardless of its severity, which they then encourage the patient to align with (e.g. “*it does not mean the child won’t learn*” after a diagnosis of autism) (Maynard, 2006). Doctors in oncology have been reported to focus on optimistic effects of treatment, which also makes it difficult for patients to discuss how they feel about the diagnosis (Leydon, 2008). This translates to descriptions of other settings, with Maynard reporting only one exception where an HIV counsellor explicitly pursues the patient’s response in order to “*crack the emotional nut*” and encourage acceptance of the diagnosis (Maynard, 2003a, :191).

Doctors have been shown to use strategies to avoid blunt and thus emotionally traumatic diagnosis deliveries. Diagnoses in secondary care are often, as well as being more serious, more complex than those in primary care. Medical examinations usually occur at a separate appointment from the diagnosis feedback, and thus straight assertions of the diagnosis without explicit reference to the evidence are unusual. Maynard (2004) demonstrated that doctors nearly always present medical examinations as evidence or confirmation of a condition, and then deliver the diagnosis. As discussed above, explicating the evidence for a diagnosis endorses the doctor’s diagnostic assessment, particularly when patients may hold a differing viewpoint. However, doctors also use the evidence itself as an indirect method of delivering the diagnosis. This is particularly common in HIV diagnosis deliveries, where the diagnosis announcement is made when discussing test results – “*your results came back positive*” (Maynard, 2003a). However, it also occurs in oncology – “*malignant means cancer*” (Yoon et al., 2015) – and developmental disabilities – “*that’s what we call mental retardation*” (Gill and Maynard, 1995). In these cases the diagnosis is delivered indirectly through syllogism: this is your test result, it is X, and therefore you have X. The patient then has to work their diagnosis out through inference, and will usually then offer some confirmation – “*and that’s what this is*” (Gill and Maynard, 1995). Thus, in distancing the diagnosis from the patient in this way, the doctor has avoided the direct diagnostic format of “you have X”, which, while encouraging “*realisation*”

(Maynard, 2003a, p36) of the news, may lead to adverse responses in its blunt delivery.

### *Resistance to Diagnosis:*

The avoidance of direct attribution of the diagnostic label to the patient also has another function. Patient resistance to diagnosis in secondary care is particularly prevalent when diagnoses are of mental rather than of physical origin, due to the stigma of mental health conditions. Monzoni and colleagues (2011b) studied diagnosis deliveries in neurology where seizures have no physically identifiable cause, and hence are likely caused by psychological factors such as previous traumatic experiences. These patients are seen in neurology clinics, and have been experiencing physical symptoms, and will thus be expecting a physical explanation (most commonly epilepsy). The authors found that doctors will assert the evidence using the brain scan results – “*your seizure was not epileptic*”. However, the diagnosis itself will be introduced in non-specific, generic terms “*there is a cause..70% of people have things in the past..traumatic things*”. These generalised descriptions indirectly class patients as a ‘person who has experience trauma’, leaving the floor open for patients to comment on this unexpected explanation, but not directly attributing psychological causes to the patient’s seizures. Doctors in this setting often avoid diagnostic labels altogether, especially in cases where patients do not engage in the psychosocial attribution. These diagnosis delivery techniques evade direct conflict with patients in a setting where resistance is common.

Monzoni and Reuber (2014, p6) also noted that some doctors manage resistance by taking a “*unilateral*” approach to delivering diagnostic information –monological explanations that discourage patient input. They demonstrated that when more bilateral approaches were taken, and patient input was encouraged, so doctors were able to construct their argument for the diagnosis using information that the patient themselves supplied. Gill and Maynard (1995) also described this practice in developmental disabilities clinics, where doctors are delivering diagnoses of children’s learning difficulties to their parents. Parents would often be resistant to labelling their children, and thus doctors would start the meeting with a perspective-display invitation, eliciting the parent’s viewpoint – “*what do you see as X’s difficulty?*” (Maynard, 1989). If

parents at this stage did not present a symptom their child may have, then the doctor will work to elicit one before continuing. As stated above, diagnoses in these settings are often presented through inference. Gill and Maynard argue that avoiding the direct attribution of the illness leaves the doctor space, should the parent not engage with the diagnosis once it is delivered, to perform a “*remedial bid*” for agreement (Gill and Maynard, 1995, p20). This often involves retrospective perspective questions – questions occurring after delivery on aspects of the diagnosis that the parents had already agreed with, e.g. “*okay, so we know X is behind*” – which the doctor will follow by demonstrating how this matches with the diagnosis given.

Another method Gill and Maynard identified that doctors use to obtain agreement is downgrading of the certainty of diagnosis after it is delivered. Similar to dementia, there is no one clinical test to see if children have a developmental disability, and it is thus the work of the doctor to gather all the information and make a tentative diagnosis, based on clinical judgement. Additionally, there is no certainty as to how the child might progress. Gill and Maynard argue that the uncertainty surrounding the testing, along with the inferential formatting of the diagnosis delivery – which only implies rather than asserts diagnosis – allows the doctor to back down when faced with persistent resistance from parents (“*this is not a cut and dry case*”). The doctor then is able to continue discussion that there is ‘something wrong’ that it may be helpful to treat, without directly facing conflict that an official diagnosis may bring. This flexibility around directly applying the diagnostic label to the patient depending on their response allows for progression of the discussion of treatment and support without parents directly agreeing with the diagnosis.

#### *Misunderstanding the Diagnosis:*

There are reports that inferential, non-direct deliveries and not combatting resistance directly can lead to some patients not processing the diagnostic information given. For example, where ‘developmental delay’ description is used instead of a specific diagnostic label, parents will often presume that there is a probability of “catch up” for their child (Abrams and Goodman, 1998). However, there is also evidence in oncology that too much information may cause misunderstandings, particularly when understanding is not explicitly

checked (Yoon et al., 2015). Maynard (2003a) argues that clear, blunt deliveries may not be the best option to ensure diagnostic understanding, as direct disclosures will disrupt processing due to the emotional impact it will have on the patient. Thus, the balance between managing negative or resistant responses and ensuring understanding is complex.

### **Implications for examining dementia diagnosis delivery**

*“Diagnostic impressions are forged by the interaction and not given by professionals.”* (Abrams and Goodman, 1998)

The CA literature has illustrated that diagnosis deliveries do not consist of a simple attribution of medical label to the patient, but patient involvement affects how the medical label is constructed. Key factors of diagnosis are doctor epistemic authority and accountability. Doctors explicate the evidence for their diagnoses to account for their clinical assessments, and patients navigate resistance in the confines of doctor medical expertise. In secondary care, doctors are aware of the negative impact of bad news diagnoses. Therefore diagnoses are often qualified, downplayed, and are communicated indirectly through syllogisms and inference to avoid blunt deliveries. These strategies appear to result in very few emotional responses, which arguably makes it easier to progress to discussion of treatment. Also, resistance can be more common in secondary care, so inferential deliveries offer space for doctors to engage patients in co-construction of the diagnosis, or to downgrade the severity to encourage agreement. There is evidence therefore that doctors encourage patient input into the diagnosis discussions in order to encourage a sufficient level of acceptance of the diagnosis to make treatment discussions possible. Direct explorations of patient understanding are rare, and as a result patients can leave the diagnostic feedback with incorrect information.

Monzoni and Reuber (2014) noted that there are common practices implemented by doctors across different medical settings. While there will be many aspects of diagnosis delivery in memory clinics that will be the same as that identified in other settings, there may also be context specific actions in

dementia diagnoses that are defined by the condition (Sacks et al., 1974). That patients receiving diagnoses of dementia are likely to have some level of cognitive impairment may cause doctors and patients to use different strategies within the interaction. Peel (2015) used CA on a small sample of dementia diagnosis deliveries from one clinician, and found it difficult to see whether certain behaviours, such as qualification of information and lack of patient response, were due to dementia-specific factors or features of bad news deliveries in general. She states that further analysis on a larger selection of data is needed to explore *“how dementia is different – especially in regard to capacity, understanding and patient insight into the condition”* (page 7).”

The aims of this thesis are therefore threefold:

1. To identify how diagnoses of dementia are communicated in diagnosis feedback meetings in memory clinics.
2. To identify how people with dementia respond to the communication of the dementia diagnosis.
3. To explore the perspectives of doctors working in memory clinics regarding the communication of dementia diagnoses in memory clinics.

Before addressing these aims, a systematic review of the literature will be presented, in order to provide context for the study within the existing literature.

**Chapter Two:  
Communication in healthcare  
interactions in dementia:  
A systematic review of  
observational studies**

This chapter is primarily a replication of a systematic review published in *International Psychogeriatrics* in February 2015 (Dooley et al., 2015). A repeated of the full systematic search has not been undertaken. However, a search was repeated using the same search terms, and monitoring of the published literature relevant to this thesis has been occurring continuously. At the end of the chapter there will be a short section containing an overview of studies using conversation analysis to observe communication between clinicians and people with dementia in outpatient settings, which were all published in the time between publication of the systematic review and submission of this thesis. These were not included in the presentation of the review in order to maintain the systematic nature of the review as it stands.

### **Background:**

High quality healthcare communication has been shown to have a positive effect on patient outcomes such as treatment adherence (Thompson and McCabe, 2012), wellbeing (Kinmonth et al., 1998), illness recovery (Kelley et al., 2014) and physiological responses to diagnoses (Sep et al., 2014). Street et al have argued that effective communication enhances understanding, decision making, and the doctor-patient therapeutic relationship, leading to patient empowerment (Street, 2013).

However, there are challenges in doctor-patient communication in dementia care that may impede effective communication. Dementia can cause problems in comprehension, word finding and short term memory loss (Blair et al., 2007). Additionally, unfounded presumptions of impaired patient abilities (Srinivas Rao and Blake, 2002) or ethical issues surrounding dementia diagnosis delivery (Karnieli-Miller, 2007) can impact interactions. Furthermore, although companions have an increasingly important role in supporting a person with dementia, their presence can result in additional difficulties for professionals in terms of balancing patient needs with that of the third party (Robinson et al., 2009).



Studies of doctor-patient communication in outpatient dementia care are scarce (Zaleta and Carpenter, 2010). Research into dementia diagnostic disclosure has shown that patients and carers experience anxiety and confusion due to a lack of support in the early stages of dementia care (Robinson et al., 2010), and that treatment suggestions are often not utilised (Wolfs et al., 2011). Additionally, theories of person and relationship-centred dementia care (Adams and Gardiner, 2005) and communication training interventions have been developed (Eggenberger et al., 2012). However, to improve communication it is important to first identify how patients and healthcare professionals are currently communicating (Street, 2013).

To date, studies that observe communication in outpatient dementia care have not been reviewed. The aim of this study was to systematically review research on naturally occurring communication between healthcare professionals, people with dementia and their companions in outpatient settings, in order to identify evidence on how communication problems are manifested in professional-patient communication and whether particular strategies have been identified as effective in communicating with these patients.

## **Methods**

### *Inclusion and exclusion criteria*

Included studies were original English language articles due to insufficient resources for translation and reviewing non-English articles. The included studies used objective methods (audio or video recording) to observe communication, and analysed communication between patients with dementia, professionals that work in outpatient dementia healthcare settings, and patient companions when present.

Studies observing residential care were excluded as they typically captured a different type of communication involving personal care. Studies only observing communication between people with dementia and/or their companions were excluded. Studies of communication using other ethnographic methods (not audio or video recordings) were excluded, as were studies focusing on group therapy and interventions that focused solely on memory retrieval.

Search strategy:

A rigorous search of all electronically registered references up to 13<sup>th</sup> August 2014 was undertaken. A hand search of relevant journals was also performed for the past 5 years, as well as a grey (unpublished) literature search (see Table 1 for details).

**Table 1: Search Resources**

<b>Databases</b>	<b>Hand Search</b>	<b>Grey Literature</b>
Books@Ovid CINAHL Embase Medline London Health Libraries PsychInfo PubMed	Aging and Mental Health Alzheimer's Disease and Associated Disorders American Journal of Alzheimer's Disease and other dementias BMC Geriatrics British Journal of Psychiatry Clinical Gerontologist Dementia: International Journal of Geriatric Psychiatry International Psychogeriatrics Journal of Advanced Nursing Journal of Aging Studies Journal of the American Geriatrics Society Journal of Clinical Nursing Patient Education and Counselling Research on Aging	Canada Theses DART European Theses EThOS UK Theses Informa Healthcare website ProQuest: (wire feeds, trade journals, dissertations, theses, news/magazines, conference papers, books, reports) WorldCat global library

Search terms were grouped into illness, clinic and communication categories, and then combined (see Table 2). They were further developed and databases chosen after consulting experts in the field of dementia and communication, and were kept intentionally broad to ensure maximum scope.

Screening:

Two authors reviewed the search results independently. Full texts of selected abstracts were obtained for inspection, again performed independently by two

authors. Any diverging views were discussed with the third author until reaching a consensus.

On the removal of duplicates, 15538 titles were retrieved after the database search. Broad search terms yielded many irrelevant results and thus initial screening was based on title. 597 abstracts were reviewed, 519 of which were excluded. 78 full texts were examined and 15 included for data extraction.

**Table 2: Search terms (with truncation)**

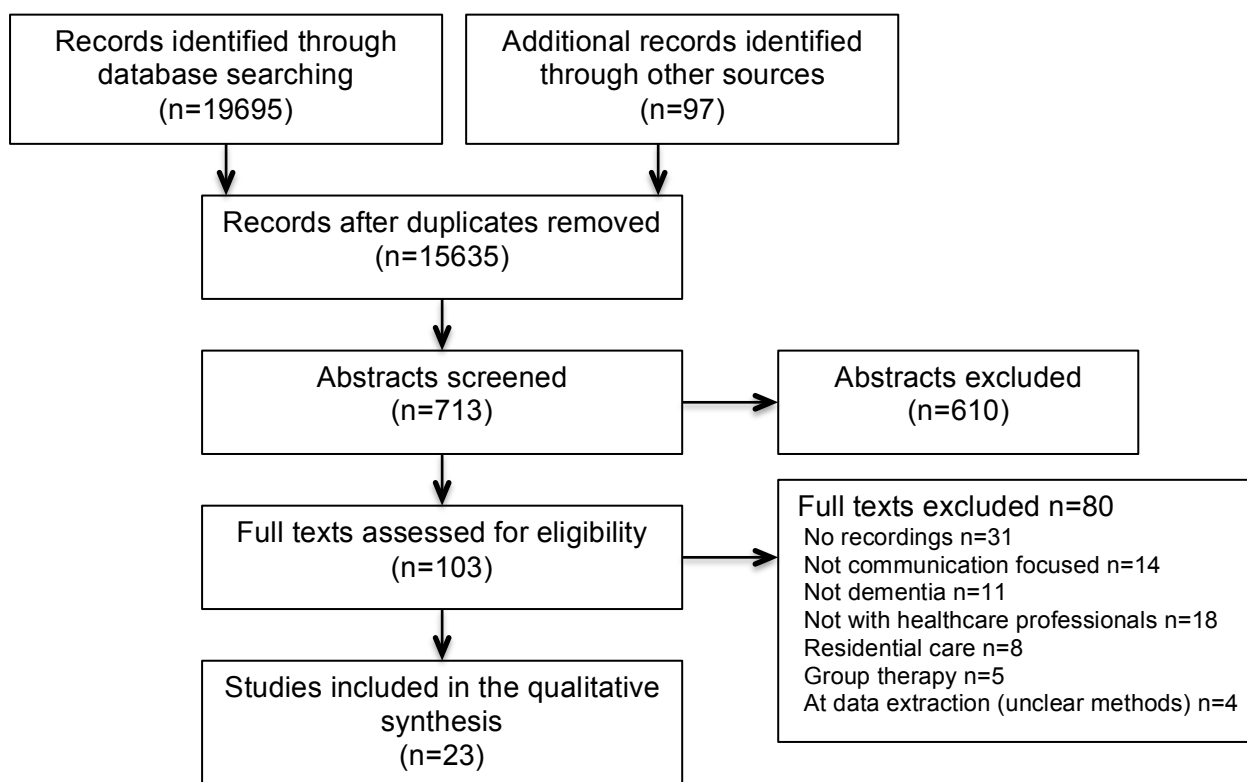
<b>Group 1</b>	<b>Group 2</b>		<b>Group 3</b>
<b>Service Users</b> - combined by OR	<b>Clinics</b> - combined by OR within column - combined by AND between columns		<b>Communication</b> - combined by OR
Alzheimer* dement* cognitive impair* next of kin caregiver companion family care* informal care* companion*	memory alzheimer* dement* neurocogni* neuro-cogni* cogni* disor* cerebr* cogni* func*	clinic centre center unit service	intera* communica* talk* discour* dialog* conversa* interview* disclos*
<b>Group terms combined by AND</b>			

Hand searching retrieved 16 articles, with 2 included in the review. The grey literature search produced 25 abstracts: all were excluded. Reference lists of 32 relevant reviews identified in the database search were examined, 11 full texts were reviewed and 2 included for data extraction. Authors of included studies were emailed to establish if there were any additional relevant studies, and 1 book chapter was identified and included. Forward and back citation searching was performed of included studies, 23 were screened, and 7 were included for data extraction. See Figure 1 for a PRISMA flow diagram.

### Data Extraction and Quality Assessment

Twenty-seven studies were included in the data extraction stage. Two authors independently extracted data using a tool designed to elicit relevant information including setting, participant information, number and method of recordings, and the analysis of and findings from the recorded data.

For 5 studies it was not initially possible to extract data due to difficulty in establishing whether the data represented directly observed findings rather than participant recollections or other forms of triangulated interpretation (Keady et al., 2004, Hutchinson et al., 1997, Robinson et al., 2009), or findings related to people with dementia rather than older adults without cognitive impairment (Hasselkus, 1992b, Hasselkus, 1992a). Authors clarified methodological aspects for 4 studies, 3 were excluded (Hasselkus, 1992a, Hasselkus, 1992b, Keady et al., 2004) and 1 included (Robinson et al., 2009). One study was excluded as the authors could not be contacted (Hutchinson et al., 1997). Four papers in total were excluded at this stage, leaving 23 studies for quality appraisal and the final synthesis.



**Figure 1: PRISMA flow diagram**

The CASP (Critical Appraisal Skills Programme, 2017) was used for quality assessment (see Appendix A). It is widely used (Dixon-Woods et al., 2007) and fitted the needs of the review in allowing examination of each study in terms of a basic methodological standard and adequate interpretation of results (Hannes, 2011). Each question and prompt was scored, with 34 items in total. Items were scored from 0-2: 0 for 'no', 1 for 'partially' (for example if the criteria was only met for one method), and 2 for 'yes'. A percentage score was calculated and a consensus was reached through discussion to give each study a single quality score.

### Data synthesis

Narrative synthesis was conducted using the protocol developed by Popay et al (Popay et al., 2006). Textual descriptions of the studies were grouped and tabulated. Two researchers independently coded the findings and put together descriptive themes of each study. Techniques recommended by Popay et al were used: primarily 'reciprocal translation' of the themes to explore relationships, and 'ideas webbing' to create a visual representation of the emerging themes.

## **Results:**

### Description of studies

The characteristics of the 23 included studies can be found in Table 3. Thirteen of the studies were conducted in the USA, 3 in Finland, 2 in Israel, 2 in Sweden, 2 in the UK and 1 in Canada. Eight studies observed communication in dementia assessment and/or diagnosis meetings, 6 in day centres, and 3 in support groups. One study observed communication in routine meetings with old age psychiatrists, 1 follow up consultations in a neurology clinic, and 3 in primary care. One study observed research consent procedures in an Alzheimer's disease research centre.

### Study quality

The quality scores from the CASP ranged from 45-89% (mean 64%). Overall, the studies were robust in reporting clear aims, analysis methods and results. There were some limitations across studies in addressing researcher bias and the selection of data to illustrate findings.

### Participants:

The majority of the studies included only patients with dementia. Five studies also included older patients who were not cognitively impaired. In two of these, the proportion of participants with dementia was not reported. Of the remaining three, the proportion of people with dementia ranged from 52-94%. Twelve of the studies included patients with any type of cognitive impairment, 6 included only patients with Alzheimer's disease and in 5 of the studies the patient diagnosis was not explicitly stated beyond cognitive impairment. Thirteen of the studies reported cognitive test scores: 7 reported MMSE (range 5-30), and one used specifically the serial 7s (range 11-26) and the WORLD (12-27) test items from the MMSE. Two reported the Clinical Dementia Rating (from "no dementia" to "mild dementia) and 2 studies used the Cognitive Performance Scale (range 2-3, moderate dementia). Patient age was reported for 18 studies, the majority were over 65. The patients' gender ranged from 15-73% female (unreported in 3 studies). Companions were present in 14 studies, although only 8 reported their characteristics. All these reported gender, and for all of them the majority of companions were female. Companions were typically spouses or adult children, occasionally another family member, and a single study included one paid companion. Companion age was reported in 6 studies, ranging from 36 to 86.

Five studies included nurses in a day centre; 2 observed a nurse running a support group and one used volunteer day centre workers. Two studies observed neurologists, one observed psychiatrists, and one primary care physicians. Nine studies included multidisciplinary staff. In 2 studies healthcare professional type was not stated. Fourteen studies reported characteristics: 14 reported gender (range 12.5-100% female), 4 reported age (range 28-73), and 4 reported number of years practicing as a healthcare professional (range 1-42).

### Study methods

Thirteen studies used audio recordings, 9 used video and one used both. Nine studies developed their own coding system to look at a particular communication feature. Three studies used conversation analysis, and 2 used discourse analysis. Two studies used the Roter Interaction Analysis System (Roter and Larson, 2002) to code patient centred communication, and one study used Behavioural Interaction Codes (Roberts et al., 1991) to record types of turns of talk in groups. One study employed thematic analysis, one content analysis, one grounded theory and one Goffman's frame theory. One study used abductive content analysis, a mixed inductive and deductive approach to interpret the communication specifically in relation to the authors' topic of study (agency and communion). In one study the recordings were used to compare the diagnosis delivered versus diagnosis reported by participants. In 7 studies quantitative measures of participant involvement were documented.





**Table 3: Summary of papers included in the review**

Reference and country	Patients	Companions	Professionals	Recordings	Focus and analysis	Relevant Key Findings	QA
<b>Setting: Assessment and diagnosis</b>							
Amizandeh et al 2007 Canada	n=30 Alzheimer's Disease (AD) 37%, Vascular Dementia (VaD) 23%, Mixed 40%  MMSE: >26 13%, 21-26 70%, 15-20 17%  Age: 65-75 10%, 75-84 57%, >85 33%  67% Female	n=30 Spouse 23%, Child 67%, Other family 10%	n=? Interdisciplinary	n=30 Audio	Emotional reactions to diagnosis  Transcribed and coded using coding scheme developed by authors to categorise emotional responses of dementia diagnosis: associated feelings and behaviours and illustrative statements	Shock and distress following diagnosis  Emotional responses stronger with diagnosis of Alzheimer's Disease rather than Vascular Dementia  Small minority expressed relief and validation  Emotional response sometimes interfered with comprehension	66%
Karnieli Miller et al 2007 Israel	n=14 All diagnosed with dementia/AD  Age: 78.5 (SD 8.4)  64% female	n=14 Adult children	n=3 Neurologists  Years in practice: 13-34	n=14 Audio	Ethical dilemmas for professionals when disclosing dementia diagnosis  Thematic analysis as a unit with pre/post interviews with professionals, and post interviews with patients and companions	Brief encounters: 4.40 to 13.5 minutes, 40 seconds to 5.4 mins actually discussion diagnosis  Avoid elaborating on diagnosis and checking understanding; evidence of changing subject, preemptive reassurance, ending conversation.  Rapid transition from diagnosis to management, more time spent on management.  Standardisation and 'preliminary stage' language. Fractured sentences and confused language when delivering diagnosis	67%

Karnieli Miller et al 2012 Israel	n=25 MMSE: 12-27 Age: mostly >65 68% female	n=? Most often family member	n=6 Neurologists, geriatricians, psychiatrists.	n=25 Audio and video	Explore triadic communication Mapped transcriptions to assess interaction and involvement of each participant Systemic grounded theory analysis. Graphic representations Semi-structured interviews with participants	Phases of visit: introduction, formal cognitive evaluation (usually without a companion), summation (results, treatment) Alternating dyadic interchanges. If third person attempts to enter either: 1. They are ignored 2. Information is "borrowed" into the dyad 3. They are silenced 4. They manage to redirect to themselves  Physician controls the conversation. Turn taking shown in small but significant verbal and nonverbal gestures Some evidence of confusion of roles Significant change between introductory and summative: outset with patient, summation with companion, but all three present. Side/private conversation with companion about diagnosis	69%
Sakai and Carpenter 2011 USA	n=86 Not all dementia Age: 72.93 (SD 8.1) 60.5% female	n=86 58% spouse, 24% child, 9% other, 8% friend. 70% female Age: 62.46 (SD 13.72)	n=7 Physicians	n=86 Video	Power dynamics in dementia diagnosis Verbal dominance (t-tests) and pronoun use (ANOVAs) recorded and linked with outcomes Questionnaire of anxiety, depression and Dementia Care Satisfaction for patients and carers	Physicians spent 83% of the time talking, patients 10.3%, companions 6.3%. This did not differ on dementia status. Companions spoke more if patients had dementia (7.7% vs. 3.7%) Physicians used fewer singular pronouns than patients and companions. Companions used fewer singular pronouns than patients Physicians used more plural pronouns than patients and companions No links with outcomes	82%
Saunders (1998) USA	n=17 41% AD, 12% VaD, 6% alcohol related, 6% non impaired, 6% mixed, 23% other, 6% undetermined 70% female. Age: 54-86 years	n=5 (not analysed) Family members	n=4 2 psychometricians, 2 trainees 75% female Age: 28-50	n=17 Audio	Use of humour in neuropsychological assessments Discourse analysis Coded for humour – then further coded for initiator, function, focus, topic ANOVA for initiator and presence of third party	Humour: 3.6% of talk: clinicians 1.4%, patients 3.7%. Third party did not influence Clinician humour more about testing issues No difference between patient humour in personal exchanges and testing exchanges Patients used significantly more dominant, self-denigrating and self-focused humour Relational humour the same for both patients and clinicians Humour can serve more than one function simultaneously. Patient self-denigrating humour indicates they are cognizant enough to reflect on their own situation	62%

Saunders (1998b) USA	(same as above)	(same as above)	(same as above)	n=17 Audio	Determine type and purpose of accounts (self description of expected and unexpected behaviour) during neuropsychological assessments Interaction discourse analysis	5 types of accounts: 1. Cognitive (metaphor or memory process) 2. Experiential (assign blame or account correct) 3. Ability and attention (position of self as poor listener, or bad artist) 4. Emotional (blame other or anxiety) 5. Comparative (to others)  Suggests that despite cognitive difficulties patients attempt to construct and maintain identity and an awareness of expected performance	55%
Zaleta and Carpenter, 2010 USA	n=54 AD 85%, Frontotemporal Dementia (FTB) 4%, Diffuse Lewy Body Disease (DLB) 2%, medication induced cognitive dysfunction 2%, Unclear 7% Clinical Dementia Rating (CDR): 67% very mild dementia, 33% mild dementia Age: 74.13 (SD 8.34) 61% female	n=54 63% spouse or partner, 22.2% child, 12.9% other family, 1.9% friend. Age: 65.57 (SD 12.5) 70.4% female	n=10 Neurologist 50%, geriatrics 40%, geriatric psychiatry 10%. Years experience: 8.2 years (SD=7.3) 40% female	n=54 Video (audio coded)	Patient Centred Communication (PCC) in diagnostic disclosure RIAS (Roter International Analysis System) for PCC Associations between RIAS and sociodemographics – binary and logistic regressions	Physicians engage in more positive rapport building and facilitation than activation, compared to emotional rapport building Positive Rapport Building: “physician agreement with the patient/companion” most frequent. Physicians also frequently showed approval. They laughed or told jokes with moderate frequency Facilitation and Patient Activation: Back channelling, eg: ‘Mhmm’, ‘ok’, most frequent. Moderate frequency: confirming own understanding, and checking understanding of patient/companion. Less frequent: asking for patient/companion’s opinion. Rarely asked for patient permission Emotional rapport building: Relatively infrequent behaviours overall Greater variability between physicians than within physicians No relationship found with dependent variables of dementia severity, gender or age	80%

Zaleta et al (2012) USA	n=90 (29 non-CI) AD 56%, FTD 2%, DLD 2%, posterior cortical dysfunction 1%, medication induced cognitive dysfunction 1% CDR: no impairment 32%, very mild 45%, mild dementia 23% Age: 71 (SD 8) 60% female	n=90 61% spouse, 20% child, 10% other family, 7% friend Age: 62.9 (13.5) Gender: 71% female	(same as above) Nurse also present at consultation	n=90 Video	Agreement after diagnostic consultations Diagnostic impressions collected from patient and companion recollection, written summary from nurse, raters from video, physician CDR value. Cohen's kappa to calculate percentage agreement Sociodemographic, physician rated patient understanding and patient satisfaction questionnaire Pearson's chi square for sociodemographics and agreement	Consensus 76.6% - moderate Patients demonstrated only fair agreement: 65.9% with companion, 61% with physician Companions better than patients with all sources, good with physician (81.9%) Physician and nurse (86.7%) and physician and video (84.7%) good but not perfect Diagnosis affected agreement: overall consensus lower for people with very mild dementia (66.7%) compared to mild dementia (71.5%) and no dementia (94.1%)	89%
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### Outpatient and Primary Care

Hasselkus (1994) USA	n=27 (not specified n with cognitive impairment (CI)) Age: 64-91 (mean=77.3) 17/27 lived with carer.	n=2 (not specified n with CI) 35% spouse, 31% children, 7% other. Age: 36-86 76% female	n=11 (not specified n with patients with CI) 5 staff physicians, 4 residents, 2 geriatric fellows	n=40 Audio	Self care behaviours as a marker of adult status in the older patient Identification of clues of incapacity or capacity on basis of caregiver interactions, and mechanisms of marginalization of patient by all 3 members of triad Categorized into marked (dementia diagnosis mentioned or evident from discourse), moderate (mild cognitive impairment or sensory impairment) or no apparent impairment	Patients with cognitive or sensory impairment demonstrated least self care behaviours and allowed caregivers to explain their impairments Marked impairment: patient involvement limited to the examination stages, especially with cognitive rather than sensory impairment, where more effort is made to include the patient Moderate impairment: poses "on the spot" challenge for professional to establish "ambiguous capabilities" of patient and caregiver – shift between the two. Caregiver tended to play more prominent role as consultation progressed	
Hunsaker et al 2010 USA	n=25 MMSE Serial 7s: 18.08 (11-26); MMSE WORLD: 20.85 (12-27) Age: range 69-92, (mean=79.3) 60% female	n=25 64% spouse, 36% child Age: 46-83 (m=67.6) 76% female	n=23 Primary care physicians (PCP), geriatrician, nurse practitioner. 30% female Age: 49.8 (33-73) Years in practice 18.8 (3-42)	n=25 Audio	Discussion of dementia related behaviours (DRBs) and comparison with RMBPC (Revised Memory and Behaviour Problems Checklist): • Direction and quality of verbal interaction • Content and initiator of topics • Dementia related companion issues • Quality of support offered	Dementia discussion: 88.5% of visits: Initiated by PCP 47.8%, companion 34.8%, patient 17.4% Quality of support moderate DRBs: 76.9% of visits: • Memory behaviours: 100% of companions reported 1 or more, discussed in 70% • Disruptive behaviours reported by 80% of companions, yet discussed 23% DRB discussion not related to PCP or caregiver demographics, relationship to patient, caregiver or PCP initiation of discussion. Burden higher for caregivers who initiated discussion	81%

Robinson et al (2010) England	n=?	n=?	n=7? Consultant old age psychiatrists	n=53? Video	Thematic analysis of recordings combined with interviews and literature review to develop intervention to improve patient centred communication in outpatient reviews of patients with dementia taking cholinesterase inhibitors Semi-structured interviews with patients and carers using prompts from videos Semi-structured interviews with clinicians on background, clinics, views, barriers and facilitators to patient centred care	Difficulties included: <ul style="list-style-type: none"> <li>• Developing a therapeutic alliance, especially with patient-companion conflict</li> <li>• Facilitating shared responsibility whilst promoting patient autonomy</li> <li>• Presenting information in manageable amounts so that patients with dementia can make informed decisions</li> <li>• Exploring person with dementia's experience and promoting quality of life.</li> <li>• People with dementia very rarely identified issues in response to direct questions</li> </ul> Consultations tended to focus on negative aspects of a patient's life Way in which doctors structured their consultations could be as important as the communication skills they used	59%
Saunders (2011) USA	n=29 non-CI n=31 CI Possible, probable AD, or mild cognitive impairment (MCI). MMSE: 18.4 (SD 6.6) only for 25. Age: 78.7, 63-92 58% female	n=30 CI n=10 non-CI Typically a family member, 1 case paid companion	n=8 Neurologists. Age: 38-65 12.5% female	n=60 Audio	Communicative coping behaviours (CCB): accounts and humour in outpatient neurology appointments Frequencies: chi square to find differences between CI and non-CI	Doctors did most of the talking, followed by patients and companions In CI patient companions did more talking than non-CI patient companions. CI patients talked approximately the same as non-CI patients, however doctors took more turns with CI patients <ul style="list-style-type: none"> <li>• 141/154 memory accounts by CI patients</li> <li>• 11/96 health accounts CI, 23 non CI, 72 doctors</li> <li>• 145/217 humour CI, 72 non-CI</li> </ul>	79%

Schmidt et al (2009) USA	n=23 Probable or possible AD MMSE: 21.4 (SD 4.2) Age: 79.3 (SD 6.3) 57% female	n=23 65% spouse, 35% adult child 78% female Age: 68 (SD 10.6)	n=20 Primary care physicians (PCP) 30% female Age: 48.4 (SD 9.8)	n=23 Audio	Participant involvement in consultation Coded participant speech for full second began/ended. Compared verbal participation using ANOVA Associations with patient verbal fluency, cognitive status, triad members' verbal participation and satisfaction Satisfaction and sociodemographics from structured interviews following PCP visit	Consultations 11.7 to 55.7 (m=24) minutes. 87% <ul style="list-style-type: none"> <li>• PCP highest speech 53%, caregiver 31%, patient 16%.</li> <li>• Caregiver participation correlated with both PCP and patient participation</li> <li>• Patient with lower verbal fluency and MMSE participated less.</li> <li>• PCP participation not related to any patient verbal characteristics.</li> <li>• Caregiver participation linked to satisfaction.</li> <li>• Patient participation not linked to satisfaction</li> <li>• Patient with male caregiver had higher participation</li> <li>• Higher caregiver education levels linked with lower PCP participation.</li> </ul>
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Sugarman et al (2007) USA	n=26 MMSE 21.8 (SD 5.2) range 9-30. Presumed AD 50% female	n=26 22 spouses, 4 adult children 65% female	n=1 Physician	n=29 Audio	Examination of informed consent agreements in outpatient department of research centre. RIAS (Roter Interaction Analysis System) coding of dynamics of three-way interaction, range of affective dimensions. Coded for key elements of informed consent process.	Length: 3.2 - 10.2 mins (m=7.1 (SD 1.7)) Average 95 statements: Physician 62%, companion 25%, patient 13% Physician averaged 10 statements for each patient statement, 3 for each companion. <ul style="list-style-type: none"> <li>• Half patient statement agreement and approval, 16% psychosocial, 7% questions, 7% emotions</li> <li>• 37% of companion agreement/approval, 19% providing biomedical information, 17% psychosocial, 8% questions, 6% emotion.</li> <li>• 19% physician agree/approval, 2% psychosocial, 30% emotion, 7% biomedical.</li> <li>• Partnering behaviours: 12% of physician, 3% patient and companions.</li> <li>• Positive association between discussion length and MMSE.</li> </ul>	88%
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**Day Care Centres**

Bohling et al. 1991 USA	n=10/11 All AD 55% Female	n=8 Daycare centre workers 75% female	n=15 Video	Responses of professionals to patient's shifts in reality. Goffman's labeled frame analysis: coding responses when person with AD breaks 'frame' of conversation	4 basic types of caregiver responses (n of examples): <ol style="list-style-type: none"> <li>1. Joins patient's frame (n=1)</li> <li>2. Briefly joins patient frame and then returns to own (n=3)</li> <li>3. Maintains own frame with occasional acknowledgement of the patient's (n=6)</li> <li>4. Maintains own frame regardless of the patient's frame (n=3)</li> </ol>	53%
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Bourgeois et al. (1996) USA	n=4 Possible AD, AD or SDAT MMSE: 7-21 Age: 74-80 50% female	n=3 Volunteer workers. Age: 51-67 Years working: 1-2 100% female	n=1-2 per patient per week over 8 weeks Audio	Memory wallet intervention Coded for n of patient novel and wallet statements of fact, ambiguous, error and other statements, and volunteer topic prompts, questions and statements in 5 minute conversational samples. Multiple baseline design with replications across subjects.	Clients: <ul style="list-style-type: none"> <li>• Factual statements increased</li> <li>• Reduced ambiguous statements</li> <li>• n=2 reduced frequency of unintelligible utterances</li> <li>• n=1 increase in error utterances</li> <li>• n=1 slight decrease of perseverative statements</li> </ul> Volunteers: <ul style="list-style-type: none"> <li>• None asked fewer than 3 prompts required</li> <li>• 2 used less prompts</li> <li>• Reduced the number of statements with 2 clients but increased with 2</li> <li>• Number of questions decreased for all</li> </ul>	66%
Kemper (1994) USA	n=5 with CI Probable AD MMSE: 10-18 Age: 69	n=3 Nursing aides, nurse or personal attendant Age: 35-50 66% female	n=40 total 3 with AD Audio	Elderspeak in care services for older adults Coded for linguistic features of Elderspeak Multivariate ANOVA to analyse effects of audience (young vs. old) and speaker (service providers (part time volunteers) vs. caregivers (day to day professionals)) Compared non-CI to CI	All spoke differently to younger vs. older adults Professionals speak with lower lexical units with dementia, fewer cohesive ties, longer pauses, more diminutives Speech style to dementing older adults appears to be an exaggeration of that to non-dementing older adults	68%



Lindholm (2008) Finland	n=3 33.% VaD, 66.6% AD Age: 79-84 33% female	-	n=4 Nurse in charge, assistant nurse, health care student, researcher 100% female	n=2 (analysed) Video	Use of laughter in proverb game Conversational analysis (CA) Laughter segments were categorized on their sequential environments: 1. When a new sequence was initiated 2. When the patient encountered problems in an ongoing sequence 3. After the correct response was uttered by another speaker at the end of a sequence	Examples of laughter: 1. As a response to sequence-initial first pair part 2. With sequence-internal problems 3. As a response to second pair part (i.e. game answer)  If laughter after first-pair part nurses often gave elaborate response. If laughter after second-pair part varying responses from nurses. Responding to laughter related to activity environment, if problem generally don't join in. If laughter directly after first pair part then elaborate response, if later more minimal	52%
Lindholm and Wray (2011) Finland	(same as above)		n=3 Nurse in charge, assistant nurse, health care student 100% female	n=? (analysed) 30 hours total Video	Conversation Analysis (CA) of extracts which revealed problematic sequences in proverb game.	Game needs pragmatic understanding and an assumption of engagement with the content.  Laughter: common response but may not mean amusement: could be to cover up.  Creative/humorous responses indicate game useful for interactions, but purpose of game is undermined if players have never known the proverbs.	47%
Lindholm (2013) Finland	n=6 (2-6 per recording) 66% AD, 22% VaD, 22% no diagnosis 50% female (1 non-CI)		n=4 (same as above, with researcher)	n=30 hours	Challenges of naturally occurring group conversations CA methodology	Challenges: nurses speaking in overlap, difficult words, using complex linguistic structures, absence of non-verbal hints  Continue conversation after patient acknowledges, but do not check understanding, heterogeneous abilities of patient group  Patients can use repair initiators to re-enter conversations: verbally and non verbally Games expose varying competence: paradox given supposed therapeutic nature	45%
<b>Support Groups</b>							

Hedman et al (2014a) Sweden	n=5 All AD CPS (cognitive performance score): 2-3 Age: 59-78 (mean 65) 60% female	n=1 Nurse, trained in the validation method. Female	n=10 Audio	Social Positioning Qualitative content analysis – segments where participants positioned themselves analysed and category system developed. Second order positioning also identified and described Field notes and participant interviews before attending group	5 first-order positions identified 1. Project manager 2. Story teller 3. Moral agent 4. Person burdened with AD 5. Coping person  Positions overall affirmed, except when less favoured. Humour, teasing, scorning and silencing used to reposition others Evidence of more discussion of difficulties than in interviews, but not by all participants	89%
Hedman et al (2014b) Sweden	(same as above)	(same as above)	(same as above)	Sense of self (expressions of possessing certain attributes) Abductive approach – interpreted in regard to the concepts of agency and communion. Implicit and explicit expressions sorted into predefined categories	Discussions of Agency: • Self-mastery: manage everyday life. • Status/victory: describing prestige/status. • Achievement: expressing pride. • Impact: empowerment. • Failure/weakness: losing abilities, use of humour to discuss • Losing face: struggling to conceal. • Ignorance: confusion. • Conflict: not a major topic  Discussions of Communion: • Love/friendship: Often ambiguous. • Dialogue: supported in group only. • Caring: ability to help others decreased. • Unity/togetherness: families and friends. • Separation: disconnected from life. • Rejection: let down by caregivers. • Disillusionment: shown implicitly. • Another's misfortune: grieving.	77%

Mason et al (2005) UK	n=11 'probable or possible dementia of any type' MMSE: 19-29 (mean 24) Age: 72-85 (79) 73% female	n=4 Admiral Nurse, Assistant psychologists, Consultant Psychologist.	n=3 sessions from each group analysed Video	Support group processes and interactions Behavioural Interaction Codes (BIC) coding verbal responses: each turn coded for BIC categories: self disclosure, information giving, personal question, impersonal question, request for feedback, support, interpretation, direct guidance, agree, negative, reflection, group process, talk, inaudible Also coded who speaker was and who it was directed Semi-structured interviews with participants on experience of group	Patients: <ul style="list-style-type: none"> <li>Disclosures = 77% group A and 66% group B's total responses.</li> <li>Self-disclosures – just over a third of total responses in each group.</li> <li>No responses reflective of group processes.</li> <li>Self-report of feeling supportive</li> </ul> Facilitators: <ul style="list-style-type: none"> <li>Questions = 50% (1/3 personal questions)</li> <li>Group A = information giving 28%</li> <li>Group B = interpretation 28%</li> </ul> Directions of interactions: 43% and 32% (A and B) of verbal responses made by facilitators Group A: <ul style="list-style-type: none"> <li>Almost 75% interactions between facilitator and individual member: 39% originating from member.</li> <li>68% of responses by a group member were directed towards a facilitator</li> </ul> Group B <ul style="list-style-type: none"> <li>47% between group members</li> <li>Member responses equally directed towards a facilitator, another group member or the group as a whole</li> </ul>	72%
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## **Findings**

Three overarching themes emerged: the communication of the dementia diagnosis, participant involvement, and participant communicative strategies when faced with cognitive impairment.

### *Communication of the dementia diagnosis:*

Five studies observed professional-patient-companion triads during diagnostic feedback. The results fell into two subthemes: emotional impact and understanding.

### *Emotional Impact:*

Amizandeh et al (2007) examined patient and companion verbal and non-verbal emotional responses to the diagnosis. More severe distress was associated with a diagnosis of Alzheimer's disease than with other forms of dementia, even when clear explanations were given as to the consequences of the other diagnoses. Karnieli-Miller et al (2007) noted however, that professionals avoided emotional exploration of the impact of the diagnosis, with minimal time spent on explanations of the diagnosis. They speculated that frequent "ums" and hesitancy might demonstrate professional anxiety in diagnosis delivery. Zaleta and Carpenter (2010) found that 'emotional rapport building', e.g. reassurance and empathy, were infrequent, and hypothesised that professionals are focusing on ensuring comprehension and treatment compliance rather than providing emotional support. However, Amizandeh et al (2007) argued that strong emotional responses might interfere with cognitive processing of the information given.

### *Understanding the diagnosis:*

Zaleta et al (2012) showed that consensus on the diagnosis between patients, companions and physicians after the diagnostic meeting was only moderate (76.6%), despite high patient rating of thoroughness (mean 4.62/5) and clarity (4.33/5) of delivery. Even agreement between physician, nurse and researcher ratings (obtained from watching the recordings) was far from perfect (84.7%). Consensus was lower for those receiving a diagnosis of very mild (66.7%) or mild dementia (71.5%), and 16.7% of companions disagreed with the clinicians,

suggesting patient's impaired cognition was not the only cause of confusion. Qualifying statements, such as 'what we might be seeing is..', were identified by the authors as a potential reason for ambiguity. Additionally, both Zaleta (2010) and Karnieli-Miller et al (2007) found that professionals rarely explicitly checked patient understanding when delivering diagnoses.

#### *Patient involvement:*

Quantitative profiling of triadic interactions provided some evidence of involvement of people with dementia in interactions, but the studies did not fully explore the reasons and implications of this. Schmidt et al (2009) and Hunsaker et al (2010) observed primary care consultations. Schmidt et al examined total speech, while Hunsaker et al examined initiation of discussion of dementia related behaviours, with both finding that professionals spoke approximately half (53% and 48% respectively) and companions a third of the time (31% and 35%). Sugarman (2007) found in consent interactions that professionals spoke slightly more (62% of statements), which may be expected given the need to explain study procedures. In all three studies, patients spoke for approximately half the time of their companions. Hasselkus (1994) qualitatively explored patient involvement in internal medicine and geriatric clinics in a hospital, and also observed patient marginalisation, describing the doctor-companion interactions as one of "two practitioners in a dyadic exchange".

However, Sakai and Carpenter (2011) examined power dynamics in diagnostic feedback and found that while professionals spoke for 83% of the time, patients spoke for 10.3% of the time and companions only 6.3%. Saunders et al (2011) also found that patients with dementia take more turns than their companions, 34% versus 25%. Professionals also spoke less, taking 41% of the turns at talk. However, Saunders' study was in a neurology setting where patients were undergoing neuropsychological examinations, and therefore the higher proportion of speech may be due to the examination process. This could also be the case in Sakai and Carpenter's diagnostic consultations, where the patient plays a more central role as they are the one receiving the diagnosis. This is explored in Karnieli-Miller et al's (2012) qualitative description of participant involvement, in which they illustrated the patient-companion-

professional triad as a series of dyads directed by the professional: focusing on the patient at examination stage, and the companion at diagnostic delivery, sometimes to the point of patient exclusion (eg: corridor conversations with the companion prior to formal discussion).

Cognitive impairment was identified as a factor affecting patient involvement. Schmidt et al (2009) found that involvement is lower and Sugarman et al (2007) found consent discussions were shorter with patients with lower cognitive test scores. Hasselkus (1994) found that if there were clues to incapacity, professionals addressed the companion over the patient, and that professionals and companions make more effort to include patients with sensory impairments than those with cognitive impairment. Saunders et al (2011) also found that companions of those with cognitive impairment took more turns of talk than those accompanying people without cognitive impairment, however companions were present for only 34% of consultations with people without cognitive impairment.

There was also evidence that professionals found interacting with people with dementia in a group presented particular challenges. Schmidt et al (2009) identified that the presence of a companion affected involvement in primary care consultations on a quantitative level: with their participation being negatively correlated with that of professional and patient. Additionally, Lindholm (2013) described problems when professionals were interacting with groups of patients with heterogeneous capabilities in day centres, indicating overlapping speech and the use of overly complex sentences when addressing patients. Mason et al (2005) found in support groups that 87.9% of interactions that involved the facilitator occurred between facilitator and individual participants. The authors suggested that this indicates that groups with people with dementia require more facilitator input than ordinary support groups.

Mason et al (2005) also observed that individual professional styles and the patient characteristics will affect support group climate, which is likely to affect involvement. They observed two support groups run by two different pairs of professionals, both member-led in terms of discussion topics. Different facilitator styles were observed to result in different patterns of group communication. For

example one group consisted of one-on-one conversations between individuals and facilitators whereas the other consisted of conversations across the group as a whole. The authors suggest that groups with heterogeneous abilities may require varying degrees of input and support and flexible facilitation is required.

*Patient face work, companion roles and professional challenges and strategies*

The patient, companion and professional demonstrated a variety of different behaviours to compensate for the perceived or actual cognitive impairment of the patient.

*Patient face work: compensatory strategies for memory, comprehension and pragmatic difficulties*

Strategies to maintain one's self image in social interactions is defined by Goffman (1967) as 'face work'. Lindholm (2008) observed that problems for people with dementia in interactions can occur: (1) immediately after the professional has spoken, suggesting comprehension difficulties, (2) in the midst of patients speaking, possibly due to word finding, and (3) after speaking, possibly due to an awareness of an inappropriate response. Hedman et al (2014b) also noted language difficulties, such as decreased fluency, content and comprehension, as evident in support group interactions. Patients deploy various coping techniques in response to these problems.

Saunders (2011) identified patient face work when undergoing assessments. Patients attempted to account for their difficulties, for example using emotional reactions, e.g. "*you rattled me so I'm off*", or blame lack of attention, e.g. "*I wasn't listening*", to explain poor performances. In addition, complex metaphors were used, for example "*my brain is off key*". Hedman et al (2014b) also described use of metaphor in discussions about dementia in support groups, with participants describing an increasing prevalence of dementia as "*a social tsunami*" that will "*put us back in the stone age!*" These subtle uses of language may evidence intact creativity and contextual understanding, and Saunders argues that this enables patients with dementia to maintain their identity despite loss of memory and other abilities.

Furthermore, there was evidence that people with dementia used humour to assert themselves, for example to raise concerns (Robinson et al., 2009), manage difficult feelings and lighten serious discussions (Hedman et al., 2014a), claim control in assessments and group conversations (Hedman et al., 2014b, Saunders, 1998b), and hide miscomprehension and maintain interactional flow (Saunders, 1998a, Lindholm, 2008). These studies argued that by using humour flexibly to both dominate talk and be self-deprecating, patients are showing insight into their expected responses and limitations and demonstrating that they are “*productive members of the interaction*” (Lindholm and Wray, 2011). However, Sugarman et al cautioned interactional partners of people with dementia to be aware of the possible negative effect of face work: patients with lower cognitive scores were found to devote more turns to agreement in consent discussions, and the authors suggested that this may represent an attempt to remain engaged with the interaction, through assent, rather than actual agreement (Sugarman et al., 2007).

There were several studies that evidenced the assistance that people with dementia give each other to maintain face in support groups (Hedman et al., 2014a, Hedman et al., 2014b, Mason et al., 2005) or day centre group interactions (Lindholm, 2013). Lindholm found that group members would compensate for others’ difficulties, for example by slowing down their talk and repeating turns. Mason et al coded types of turns at talk in two support groups, and although they found a low incidence of what they classified as ‘helping behaviours’ (9% of talk in group A and 16% in group B) they found that in interviews patients reported feeling supported, and suggested that this might be due to the sense of containment within the group. Hedman et al also examined support groups and found that patients supported each other’s expressions of sense of self, especially in discussions of dementia as a burden and in developing coping strategies. The authors compared (anecdotally) the group discussions with individual interviews with the people with dementia prior to the support group, and found that people emphasized their difficulties more in a group with other people with dementia than in discussion with the researcher. Additionally, although not all people with dementia spoke up about their difficulties in the groups, all reported a feeling of collective identity and support.



*Companion as patient advocate and professional informant:*

Hunsaker et al (2010) found that companions were twice as likely as patients to initiate discussion of dementia related behaviours with doctors, and Sugarman et al (2007) similarly found that companions delivered more biomedical information about the patients than the patients themselves. In both studies, the people with dementia were in mild or moderate stages of the illness, and Sugarman et al found no statistical relationship with illness severity and the information provided by companions. Hasselkus (1994) suggests that companion interjections can result in patient marginalization due to assumptions of (in)capacity, which may be attributable to ageist or paternalistic attitudes, or long standing family relationships. Alternatively, Hunsaker et al (2010) argued that companion assertiveness is important to increase support for patients. However, they found that while memory difficulties were more readily discussed, disruptive behaviours (e.g. irritability or wandering) were under-reported. They suggested there might be discomfort for the companion in divulging sensitive information in the presence of their relative. Similarly, Hasselkus describes episodes of 'protective caregiving', where companions subtly communicate with professionals 'without overtly highlighting the patient's incapacity'. However, Hunsaker found that companion reports of behaviours were more likely when their burden was higher, suggesting that in an attempt to save embarrassment for the person with dementia, companions may only raise issues when the need is great.

*Professional challenges and communicative strategies:*

Several studies noted the particular importance of the increased conversational role of the professional in dementia care, given the likely cognitive impairment of patients (Hedman et al., 2014a, Mason et al., 2005). However, Robinson (2009) noted that psychiatrists found certain areas challenging, namely balancing patient and companion needs, presenting information for shared decision making and exploring patient experiences. Additionally, Bohling et al (1991) observed that patients may change the topic or meaning of conversations in a place that may not be socially expected, and professionals often cope with the confusion by returning to their own topic immediately or after only a brief attempt at understanding the patient, resulting in patient frustration. These difficulties also occurred in support group settings, with Hedman et al

(2014b) presenting evidence of some people with dementia explicitly showing annoyance when other patients dominate the conversation or repeat themselves and the facilitator does not intervene.

Hence, interactional work to ensure mutual understanding was a recurrent theme. Bourgeois and Mason (1996) aimed to enhance patient-professional communication by developing a memory wallet intervention, which they showed decreased “*ambiguous*” patient statements, but had varying effects for the four patients trialled. Kemper (1994) found professionals subtly adapted their speech when addressing elderly people and specifically used longer pauses, shorter sentences and fewer cohesive devices when interacting with people with dementia, although the study did not address if this enhanced the interaction. Lindholm and Wray (2011) examined a game played in day centres, and argued that game playing assumes that the person with dementia has entered the “*world*” of the game with the professional – that it is a game rather than a test. They note that if the game were introduced unclearly, any work the professional may do to maintain the patient’s dignity within the game would be lost.

Strategies to address cognitive impairment in interactions were also identified. Lindholm’s papers (Lindholm and Wray, 2011, Lindholm, 2013) raised the issue of whether factual correctness should really be the aim when conversing with people with dementia in a day centre, or whether compensatory work by the professional may result in less testing interactions. They also, perhaps conversely, found that elaborate responses highlighting the patient’s shortcomings might provide patients with more of an opportunity to repair understanding and continue the interaction, or to insert humour into the exchange, therefore maintaining common ground with the professional. However, different professionals and patients responded differently, making blanket recommendations for communication difficult. Hasselkus (1994) reported that some professionals carried out their tasks while masking their knowledge of the patient’s incapacity, although no examples of this were described. Hunsaker et al (2010) noted that when professionals asked directly about dementia related behaviours in GP consultations, ensuing discussions on the topic were not more likely to occur. They argued that this might be due to patients and carers not wanting to explicitly foreground sensitive problems in

front of each other. They therefore suggested that professionals utilize more subtle techniques to elicit discussions, for example by being aware of and responding to oblique allusions to difficulties. Robinson et al (2009) suggested that practical and structural factors, such as seating arrangements and whether patients and carers are seen separately, may also be important to encourage patient centred care in outpatient settings.

## **Discussion:**

The overarching themes in the 23 studies of naturally occurring communication between people with dementia, their companions and healthcare professionals in outpatient settings were the diagnostic delivery, involvement of people with dementia, and participant strategies used in adapting to the impact of cognitive impairment on interactions.

There was evidence that differing patient capabilities and companion and professional roles in these healthcare interactions can create difficulties for all participants. Cognitive impairment impacts on the patient's involvement, and a preserved awareness of their incompetence at certain points in the interaction is manifested in considerable attempts to save face. The companion's dual role as an informant and an advocate of the patient is a recurring theme, and also one that is evident in other literature on triadic healthcare interactions, for example in doctor communication with adolescents (van Staa, 2011) and patients with psychosis (McCabe et al., 2002). Professionals can understandably struggle in striking a balance between fulfilling their institutional role and providing emotional support to both patient and companion. This has not only been noted in other diagnosis settings, such as HIV and learning disabilities, but is also a feature of delivering bad news in general conversation, where speakers will convey information in an abstract, fact-based way and avoid emotional language (Maynard, 2003a). Further additional challenges for professionals are manifest by the presence of a third party with additional needs and expectations. These sometimes-conflicting roles and differing participant concerns often shaped the interactions and were identified as potential explanations for the communication difficulties observed.

The ethical dilemmas that arise with diminishing capacity also emerged in the studies. For example, Lindholm (2011) illustrated how professionals will vary between highlighting incorrect patient responses and glossing over misunderstandings. In day centre activities it may not be deemed ethically problematic to save the patient embarrassment by moving on in the interaction. However, whether this is still acceptable when delivering diagnoses or making treatment decisions or whether ensuring factual understanding should be the primary goal at this stage is uncertain. There is now a general acceptance that dementia diagnosis disclosure should be the norm (van den Dungen et al., 2014). However, there was evidence of both subtle and overt marginalisation with studies showing companions speaking twice as much as patients in primary care, and corridor conversations taking place prior to diagnosis delivery. This may lead to patient disempowerment, future withdrawal from social situations, and feelings of frustration and diminished self-worth (Sabat, 2001). However, given the emotional impact of the diagnosis for all involved, and the frustration and anxiety patients are shown to experience when they have been misunderstood or do not understand, the ideal level of patient involvement remains an ongoing discussion (Abley et al., 2013). Additionally, while patients and companions might want to know all the facts about their illness, it still needs to be communicated in a sensitive manner. While there is some research on 'truth telling' in dementia care (Pinner, 2000), it is clear that more research is required on how this is best done, in terms of both how it is communicated and the physical setting, and the effects this has on patient and companion involvement and understanding. For example, in those studies that explored diagnostic delivery it was found that mitigating language left room for patients and companions to misinterpret important diagnostic information. However, while clearer and more straightforward delivery may improve understanding, it may cause a more negative emotional impact. Similarly, 'protective caregiving' could minimise distress and save face, but may result in barriers to shared decision making and patient centred communication.

#### *Strengths and limitations:*

The strengths of this review lie in the systematic and transparent methods of data searching, extraction and synthesis, and the focus on direct recordings of communication. The inclusion of a variety of professional types and settings

increases generalisability. However, given the heterogeneity of qualitative research, the variation in reporting and the need to exclude studies based on lack of methodological clarity, the resulting quality of included studies was only moderate. There was wide variation in the type and stage of dementia, which will impact on the communication, but this information was sometimes lacking from the studies. Finally, only papers published in English were included.

*Conclusions and future research:*

Three-way patient-companion-professional communication in the management of dementia raises a number of ethical questions: in particular, how to strike a balance between the different communicative needs of patients and carers; how to moderate the emotional impact of a diagnosis of dementia while ensuring clarity; and whether to minimise or expose interactional difficulties and misunderstandings to enrich patient understanding and participation.

Future research should specify the interactional context and degree of cognitive impairment along with communicative strategies that appear to be effective. Rather than assuming that particular communicative behaviours are positive or negative, specific consequences for patients and companions should be explored. An area of clear importance is the delivery of a diagnosis of dementia, and the emotional impact for all parties, including professionals, who may require support in attending to the emotional import for patients and companions. Further research is therefore important to inform guidance for healthcare professionals to ensure clear communication and understanding in outpatient care whilst still maintaining a sensitive and empathic approach.

**Conversation analytic studies of outpatient dementia interaction published from 2015 to 2016**

As stated in the introduction to this chapter, a repeat systematic search, which would be necessary to be absolutely certain that there were no relevant papers published between August 2014 and November 2016 that have been missed,

has not been conducted. However, regular literature searches using the same search terms were undertaken, as well as forward citation searches of the papers included in the review, reading related papers and their references lists, and discussions with researchers in the field. In these searches, 6 particularly relevant papers published since 2014 have been identified as important to discuss. All these papers use conversation analysis (CA) to examine interactions between healthcare professionals and people with dementia.

Two papers have been published from a group of researchers aiming to create a diagnostic conversational profile of people with dementia (Jones et al., 2016, Elsey et al., 2015). Video recordings of the history taking section of the initial assessment in memory clinics were examined to see how people who ended up receiving diagnoses of dementia interacted with the clinician (n=15), compared with people who ended up with non-progressive, functional diagnoses (n=15). People with dementia were less likely to be able to answer questions about personal information, and often appealed to their companions to answer questions for them. They often showed a lack of ability to hold information in working memory – for example forgetting things the doctor had said, or that they had already told the doctor. This also resulted in difficulties in answering multi-part questions, for example *“do you know why you’ve been referred to this clinic, and who is more concerned?”* Additionally, people with dementia took longer to answer questions, and provided less detail than people who did not receive a dementia diagnosis. These studies provided insight into specific features of interaction that are affected even in early stage dementia.

Another study of memory clinic communication (Hesson and Pichler, 2016) examined patients’ “I don’t know” responses to questions in the cognitive test. Patients can say “I don’t know” as an indication of lack of knowledge, but there are other functions such as qualifications of responses (*“oh I don’t know, but I guess..”*), filling up the gap while working out the answers (*“I don’t know, I just go by..”*), and indicating resistance to answering questions (*“I don’t know there’s so many different ones to start with”*). The authors found that people with more severe dementia would use more of the “I don’t know” utterances that indicate lack of knowledge, and argued that awareness of this could aid clinicians in recognising the level of a person’s cognitive impairment.

A highly relevant study to this thesis was by Peel (2015), who observed how one clinician delivered dementia diagnoses to 5 patients in a memory clinic. She found that patterns of dementia diagnosis delivery were very similar to diagnoses in other settings (as discussed in Chapter 1): the doctor delivered the diagnosis indirectly using evidence from the brain scan, and patients and their companions rarely responded. Her study corroborated previous findings that doctors avoided 'dementia' and 'Alzheimer's disease' labels, and found that these labels were only observed if the patient's companions instigated their use. Additionally, in the one case she examined where the diagnostic term Alzheimer's disease was used by the doctor, the patient then displayed a lack of knowledge of what the diagnosis entails in his response ("*it (my memory) is coming back*"). This led Peel to argue that the use of diagnostic terms may not facilitate the patient's explicit understanding of the diagnosis.

The remaining three studies were less relevant to this thesis. Two papers observed the challenges involved in implementing cognitive tests when an interpreter is needed (Plejert et al., 2015, Majlesi and Plejart, 2016). These papers highlighted how difficult it was to see what aspects of the situation were impacting on the cognitive test when patients did not speak the language of the tester. Clinicians, interpreters and patients all used non-verbal communication such as gesturing and body positioning to maintain interactional flow.

The last study was a continuation of the studies in the systematic review by Lindholm (2015), who observed how care workers responded when one person with dementia in a day care centre produced "confabulations" – i.e. told them something that the care worker knew was not the case. There were a continuum of responses care workers would use – from open or embedded challenges to acquiescence and encouragement. There was no evidence that the person with dementia preferred one response to another, but the authors argued that as confabulations often contain links to the person's past, engagement may help care workers gain insight into their experiences.

## **Conclusion**

The papers summarised above thus complement the findings of the review. The difficult balance in maintaining the at times competing factors of the understanding, involvement and emotional well being of the person with dementia, and the healthcare professional's honesty and need to complete clinical tasks, can be found throughout the studies. The impact of the patient's lack of insight into their symptoms, and potential lack of orientation to the topics of discussion, was demonstrated across different clinical settings. These themes will be developed throughout this thesis.

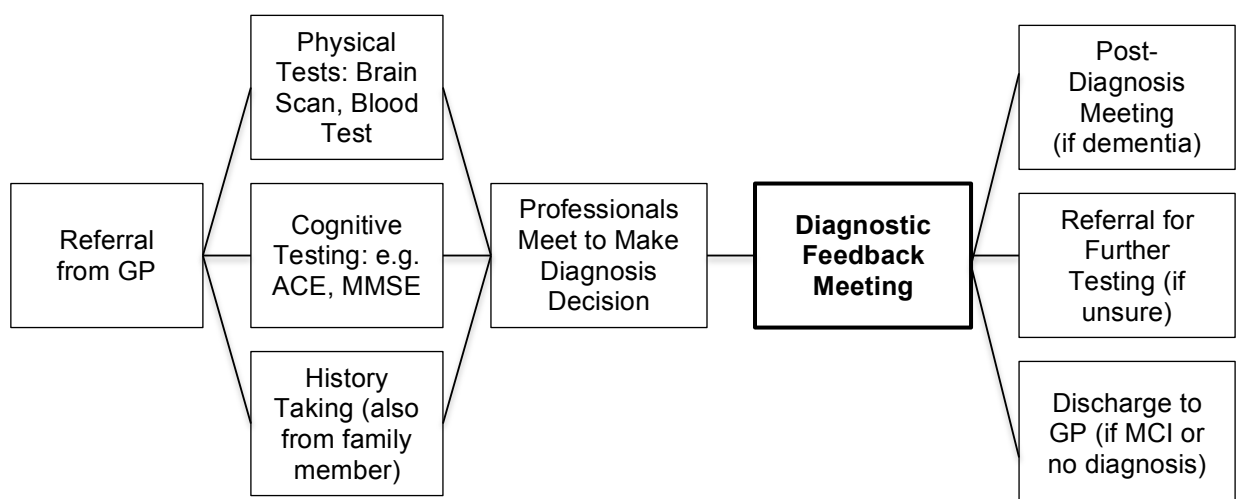




# **Chapter Three: Context, Methodology, and Participant Information**

## Context – The Memory Clinic

Data were collected for this thesis in two sites in the UK – Devon (Site A) and London (Site B). While the memory clinic structure is essentially the same nationally, following the NICE guidance for dementia diagnosis and assessment (National Institute for Clinical Excellence, 2006), each clinic is set up differently within the recommended pathway (summarised in Figure 2). The diagnostic process within this pathway differed between the two sites, details of which will be explained below.



**Figure 2: Memory clinic process**

### Referral from the GP

A referral to the memory clinic will come from the patient's GP. Some people may have gone to the GP themselves worrying about their memory problems, some have been taken by a family member or friend, or the GP may have noticed symptoms and recommended a referral. The GP will take the history and usually do a short assessment with the patient. They will also refer the patient for blood and urine tests, as well as administer any other physical examinations to rule out cognitive impairment caused by other factors such as strokes. This information will therefore be available to the memory clinic when triaging the patient for assessment.

### Cognitive Assessment, History Taking, and Brain Scan

The cognitive assessment and brain scans are organised by the memory clinics. The cognitive assessments can take place in the memory clinic or at the

patient's home. In Site A psychology assistants conduct the assessments, and in Site B the clinicians vary according to clinic and can be a psychologist, nurse, or in some cases the same psychiatrist or geriatrician who delivers the diagnosis.

The cognitive assessments differ between clinics, but the majority of the patients in the study took the ACE-III (87%), and a proportion took the MMSE (9%). The cognitive assessments take on average 30 minutes to an hour. The ACE-III has a total score of 100, with a score lower than 82-88 (depending on the patient's pre-morbid IQ) indicating difficulties beyond that which would occur with ageing. The MMSE has a total score of 30, with the cut-off point for dementia being lower than 26. The ACE-III and MMSE are brief cognitive tests that are used clinically to detect dementia, but their specificity can be lacking with people in earlier stages or with unusual symptom presentations (Velayudhan et al., 2014). More detailed neuropsychological tests are not routinely administered, but should there be a clinical uncertainty about the diagnosis the patient may be referred for further testing. This occurred for two of the patients in the study, but these test results were not collected or reported to the patient in detail in the video recorded meeting.

The patient will be interviewed on their symptom history in the same appointment as the assessment. The memory clinics ask the patient to attend the appointment with a family member or someone who knows them well, and this companion plays a key role in the history taking (examples of letters in Appendix B). In Site A the patient's companions have an in-depth interview on the patient's history while the patient undertakes the cognitive testing, and thus the patient is not present. Site B has no formal separation of patient and their companion at this stage, although it reportedly commonly occurs.

The patients also have a CT scan, which gives an indication of any structural changes to the brain. The scan is used primarily to rule out any tumours or major strokes that may account for any cognitive impairment, and is thus not a diagnostic tool for dementia. However, there is a link between Alzheimer's disease and atrophy (loss of volume) of the brain in the region around the hippocampus, and thus doctors use this as an indication of likely dementia.

Additionally, the scan can show a change in the blood flow of the brain, which is caused by small vessel disease and can cause vascular dementia. In early dementia however the scan may show no more changes than one would expect with normal ageing, and a cognitively intact person may have some of these changes in the brain but not have dementia. The doctor thus will not be able to tell the patient's diagnosis from the scan alone.

In Site B these assessment and brain scan appointments take place separately, usually over one or two months, although this can take longer. Site A has a different approach, where the assessments, history taking and diagnosis feedback all take place on the same day, and for the clinic based in the hospital the brain scan is also on the same day. Therefore, while in Site B the patient will have one appointment for the brain scan, one for the assessment and another for feedback, in Site A the patient has one appointment for all the stages, which takes about 4 hours.

The average number of days between GP referral and the diagnostic feedback meeting in Site A was 69 (approximately 10 weeks). The referral data was missing for two of the trusts within Site B, but for the remaining trust there were on average 134 days (18-19 weeks) between GP referral and diagnostic feedback.

### *Diagnostic Decision Making*

Once all the information from the history taking, physical tests, and cognitive tests has been collected, the psychiatrist or geriatrician will meet with the rest of their team to assess the evidence. In Site A, where everything happens on the same day, this meeting takes place once the patient has completed the tests and their companion has completed the carer's interview. The meeting consists of a half hour discussion between the doctor, the psychologist who administered the test, and the nurse who conducted the companion interview. The patient and their companion wait in the waiting room during this time. The Site B clinics differ in their approach, but tend to have weekly or fortnightly meetings where the cases are discussed in the larger team and diagnostic decisions are made ready to be fed back at the patient's next appointment.

Dementia is a complex, clinical diagnosis. People can score under the threshold in the cognitive tests not only if they have dementia, but also if they are anxious or have low mood, a low level of education, sensory impairments, or do not speak English as a first language. Similarly, as stated above, the brain scan cannot provide a clear indication that the patient has dementia. For this reason, the doctor is reliant on the history when coming to their diagnostic conclusion: the collateral information from the patient and especially the patient's companion is key. A patient may have perfect cognitive test scores and there may be little evidence for dementia on the brain scan, but if he or she has experienced a change in cognitive functioning, which cannot be explained by depression or anxiety, then this might point towards a diagnosis of dementia. Of particular importance is that this is a change in functioning over time, and hence patients may need to be tested over time to detect deterioration. Likewise, if the patient did not do well on the cognitive test and had some vascular risk factors or atrophy on the scan, but has recently gone through a dramatic life change such as a partner dying or retirement, this may not lead to a diagnosis of dementia. Reaching a diagnosis of dementia therefore involves balancing up numerous pieces of evidence, and thus there can often be uncertainty surrounding diagnostic accuracy.

#### Pre-diagnosis Counselling

For patients in Site A, there is no contact from the memory clinic prior to the day of diagnostic feedback other than the appointment letter (Appendix B). This letter outlines what will happen on the day in terms of a scan followed a meeting with memory clinic staff. However, the possibility of a dementia diagnosis is not mentioned in the letter, with the following paragraph describing the potential outcome of the day:

*“The purpose of the Memory Clinic is to assist people in Devon who may have problems with memory. Later, when we have a clear understanding of your circumstances we may be able to advise you on ways of helping with the memory difficulties.”*

While the psychology assistant may explain the testing and the fact that this may lead to a dementia diagnosis when they meet the patient and their

companion in the clinic, there is no formal process of informing or consent for the diagnosis to take place.

Some clinics in Site B explicitly use the initial assessment appointments as pre-diagnostic counselling – i.e. prepare the patient for a possible diagnosis and discuss their preferences for treatment and support should they have dementia. However, there is only one clinic (from nine) with a formal process in place, despite recommendations for pre-diagnostic counselling in the UK national memory clinic guidelines (Hodge et al., 2014). Similar to Site A, the appointment letter for the diagnosis feedback does not mention the possibility that the person will receive a diagnosis of dementia (Appendix B).

### *Diagnostic Feedback Meeting*

The next stage of the memory clinic process is the appointment where the patient receives (or does not receive) a diagnosis of dementia. It is these meetings that are video recorded and examined in this thesis. In Site A this meeting occurs on the same day as the patient's assessment, at the end of their 4 hours slot at the memory clinic. In Site B this meeting may occur from weeks to months after the initial assessment. The goal of this meeting is to diagnose the patient, start them on appropriate treatments, and refer and signpost them to relevant support services. In all the clinics in the study, the doctors (psychiatrists or geriatricians) lead the diagnostic feedback meetings. In Site A they are usually the only clinician in the room, but in Site B the clinician who conducted the initial assessment, or the clinician or support worker who will follow the patient up, are often also present. These clinicians are usually mental health practitioners working in the NHS, or support workers from the Alzheimer's Society.

People who are told that they have mild cognitive impairment, or that their difficulties are not sufficiently severe to receive a diagnosis, are discharged with instructions to go back to their GP if they notice their memory problems getting any worse. The patients who are told their memory problems are due to psychological factors may be referred to the mental health team, prescribed anti-depressants, or referred for therapy, and will then also be discharged. When the doctor is not clear what is causing the patient's memory problems,

they may refer the patient for further cognitive testing or a more detailed brain scan. Another appointment will be booked, usually with the same clinician, to discuss those results.

### Post-Diagnostic Meetings

Should a patient receive a diagnosis of dementia, they usually meet with someone connected to the memory clinic between a week and a month after their diagnostic feedback. Nurses, occupational therapists, or more increasingly Alzheimer's Society support workers run these meetings. The purpose is to check how the patient has reacted to medications if they were prescribed, and also to discuss planning for the future, such as setting up lasting power of attorney (giving permission for another person to take over financial and health decisions in the event of loss of capacity). Information is provided for the patient and their family on memory services available in their area, such as memory cafés or dementia-friendly groups. The number and nature of post-diagnosis meetings varies according to the individual clinic, but memory clinics generally do not provide long term care for patients unless they have complex needs. If the patient requires further support in the home they will be referred to social services. The patient's GP will be in charge of monitoring medication once the patient has been discharged from the clinic.

## **Methodology – Data Collection and Conversation Analysis**

### Data Collection

Data was collected from 9 memory clinics across 4 NHS trusts (Devon Partnership NHS trust, East London NHS foundation trust, Camden and Islington Foundation NHS trust, Barts Health NHS trust). Data collection ran from May 2014 to October 2015.

Professionals were identified through established links with the participating trusts, and contacted at first through email, and then by telephone. Once recruited, clinicians or their administrative staff identified eligible patients. All patients attending the memory clinic were eligible other than those who did not understand English sufficiently to take part in the diagnosis feedback without an interpreter. The use of an interpreter was deemed a disruption to the



communication of the diagnosis, which, while an interesting topic of research (Plejert et al., 2015), is beyond the scope of this study. A letter outlining the study was sent from the clinician to potential participants with their memory clinic appointment letter. When the patient and their companion arrived at the clinic, a researcher approached them to discuss the study and obtain written, informed consent. Their meetings with the clinicians were then filmed without the researcher present.

### Equipment

The memory clinic meetings were filmed using GoPro HERO3+ black edition cameras. The majority of the meetings were recorded using two cameras, placed so as to capture as much detail as possible, ensuring all participant faces were captured. The meetings were also audio recorded using dictaphones to ensure maximum chance of high quality audio capture. Audacity audio processing software was used for CA transcription of the diagnostic feedback, as well as QuickTime for non-verbal information. The CA transcription was done using the Jeffersonian method (Jefferson, 2004), see Appendix C for transcription notation. This method of transcription uses symbols to identify all features of talk, including the timing (such as when different speakers overlap and the exact length of pauses), as well as changes in pitch, volume, and speed. I transcribed 46 diagnosis deliveries for CA analysis and the remaining were transcribed by the company CA Transcription.

### Conversation Analysis

Two of the research aims of the thesis are to describe how dementia diagnoses are delivered in memory clinics and how people with dementia respond to the diagnosis. The literature review identified broad themes affecting communication of diagnosis (namely emotional impact and misunderstandings) and communication with people with dementia in other outpatient settings (balancing patient and companion needs and compensation for cognitive impairment), and recommended further exploration of the diagnostic interaction itself. The method chosen for this exploration within this thesis is Conversation Analysis.

CA is “a qualitative approach to the study of social organisation of human interaction” (Heritage and Atkinson, 1984). It was developed as a method to analyse talk as it occurs naturally, “directly and with repeated inspection, (to) discover and elucidate orderly phenomena evident in the domains of actual talk and social interaction” (Sidnell and Stivers, 2013, :27). CA is an unmotivated, inductive method that aims to identify and describe regularities in the sequential organisation of our interactions that enable us to communicate meaningfully.

The theory behind CA is that it is the study of talk *in interaction*. What makes it different from other sociological, linguistic, or psychological studies of talk is that while it is interested in language, its primary concern is how social actions are organised and constructed within interactions. In this sense, CA is a study not of what language an utterance contains, but what social action is being achieved within that utterance. In CA, participants within interactions co-construct the meaning of social actions by their construction (i.e. design of our utterances) and placement within a sequence of talk. The role of sequence within interaction creates expectations for participants to respond in a certain way. For example, if one participant asks a question, the expected response is for the other participant to answer the question. These sequences become rules, which participants in interactions are accountable for sticking to. These are evidenced by the fact that, should a participant not adhere to the expected sequence, there is generally a public display of accounting for that rule-break. For example, if the participant did not understand the question and thus cannot answer it, they will initiate a “repair” – such as asking the speaker to repeat their question.

CA as a study of sequence and design of talk allows an interesting approach to doctor-patient interaction, in that it allows a direct examination of how an institutional action is acted upon by participants of that institutional interaction. Specific to this study, it allows us to take the concept of “diagnosis delivery” and see how this action is undertaken by doctors and responded to by patients. This allows a description (within the CA framework of sequence, turn design, and social actions) of how these actions occur in “ordinary life” (Mondada, 2013, p34). Therefore, while other methods of analysing communication (e.g. coding certain interactional features) can seek and identify behaviours and count their

frequency, they do not report how these behaviours are communicated and how they affect the interaction as it unfolds. CA, through microanalysis of how our communication develops within a sequence of talk, is able to report on the subtle nature of interaction in a way no other method can.”

CA is an established, rigorous method to identify interactional behaviours in different contexts in many different disciplines. As the vast majority of tasks accomplished by clinicians occur via communication, CA has been identified as a useful tool in examining healthcare interactions (Parry and Land, 2013). As discussed in the introduction, CA has been used to identify broad features of medical interactions such as the organisation and structure of consultations (Robinson and Heritage, 2005), and how participant roles manifest in medical interactions, such as how patients are able to assert ownership of their experiences (Heath, 1992). Furthermore, the ways that doctors design their turns at talk have been shown to affect the participation of the patient in the interaction. An example of this is that doctors formulate questions to expect certain answers: for example *“no blood or anything?”* expects a negative response, and thus makes it harder for patients to say they are experiencing that symptom (Heritage, 2009). CA, in describing these behaviours within doctor-patient talk, provides *“a sound basis for assessing the likely interactional and communicative consequences of adopting one form (of talk) rather than another”* (Drew et al., 2001, p67).

CA has also been highlighted as a useful method in examining interactions where one participant has dementia. While other methods to explore communication may focus on the deficits of the person with dementia, CA sees interaction as a collaborative achievement, and the successful progression of the interaction thus depends on both parties (Perkins et al., 1998). This can lead to useful discoveries in how to improve interaction with people with dementia. For example, Hamilton (1994) showed that turn taking is present even in late stage dementia, but the split second timing required in multi-party interactions causes difficulties for someone with dementia to enter conversations. Identifying specific communication issues for people with dementia such as this can result in those who are interacting with people with

dementia modifying their behaviours in a productive way to enhance communication.

Conversation Analysis is an established and useful tool for examining both medical interactions and interactions with people with dementia. However, the vast majority of the literature on dementia diagnosis delivery consists of interviews with participants, which are limited by memory and post hoc rationalisations that the interview structure can induce. The advantage of CA as a method is that it allows examination of the diagnosis deliveries themselves, not how people report experiencing them, or limited aspects of the interaction as dictated by a coding scheme. As stated in the previous chapter, there is only one paper using CA examining dementia diagnosis delivery to date (Peel, 2015). This study illustrated data from three meetings with one clinician, and states “*larger data-corpora of talk within the memory clinic context*” (page 7) are needed.

#### Data Analysis Methodology

CA methodology was thus employed to examine the diagnosis delivery and patient responses (Sidnell, 2013). Initial analysis involved repeated watching of the videos, mapping topics and noting the time started and time spent on each topic within the meetings. This was recorded in tables and then repeated in NVivo to link the mapping to the text in the transcripts. The structure of the meetings was identified, which is described in Chapter 4.

After identifying the meeting structure, the sections of the diagnosis feedback where the diagnosis is named and the patients responded to the diagnosis were identified. These sections were transcribed in more detail, using Jeffersonian notation (see Appendix C). The next stage consisted of identifying turns where the action of “diagnosis delivery” was undertaken by the doctor. These were defined as the first instance where the diagnostic label was attributed to the patient (more detail in Chapter 5). Detailed analysis of these sequences identified systematic patterns of the diagnosis delivery and responses across the consultations. The precise design of the turns was analysed, i.e. the words used and the order in which they were used. This facilitated further description of the commonalities and differences across the 81 cases.

The analysis was conducted individually, but also frequently in groups in CA data sessions. The data were presented at different CA data sessions nationally (DARG, EMCA conference and CARP), and at one international CA conference (ICCAP, Ghent 2014). I also presented at 3 data sessions when spending a semester studying CA at UCLA, which was the place where CA was founded and offer undergraduate and graduate programmes in the method (Sacks and Jefferson, 1995). Additionally, in attending national data sessions, UCLA seminars, and CA conferences throughout my PhD, I gained insight and understanding from others working in the CA field, which I was able to apply to my work. On return from UCLA an average of 3 data sessions a month were held with my supervisor and colleagues at Exeter University.

Presentations to clinical audiences at conferences (one national, one international and four within Exeter University Medical School) and informal discussions with clinicians taking part in the project also informed the analysis. The ethnographic information that the clinicians were able to provide was extremely important in examining the data. Additionally, spending time in the clinics when recruiting participants, as well as prior experience of working in a memory clinic, provided important insight as to the context of the diagnostic interaction.

NVivo (version 11) was useful throughout the data analysis process to be able to easily access different segments of the meeting, and also as a method of coding different doctor and patient behaviours throughout the dataset once practices had been identified using CA. This was particularly useful given the size of the dataset. Word and Excel tables were also created and much adapted throughout the process to have more focussed collation of specific aspects of the analysis.

#### *A note on the validity and reliability of Conversation Analysis*

When conducting the systematic review, it was evident that the CA papers scored the lowest marks on the CASP Quality Assessment Scale. This was invariably due to the reporting of the analysis itself – with the studies scoring little or no points in their description of minimising researcher bias in data

collection and analysis and in selecting data for presentation. It is thus worth noting that as CA does not adhere to the usual qualitative analysis techniques (of investigating meanings through interpretative analysis) that are used in more commonly used qualitative methods such as thematic or discourse analysis (Parry and Land, 2013), validity and reliability are dealt with in a different manner.

CA comes from an ethnomethodological tradition and is an inductive method. As Roberts and Robinson explain both *"the process and the product"* of CA are *"grounded in the communicators' orientations, which are themselves grounded in the observable features of naturally occurring interaction"* (2004, p337). The product of CA is a therefore representation of the data itself. In this sense, much of the validity of CA is through making the findings transparent: the behaviours described should be apparent for the reader in the presentation of the data (Kirk and Miller, 1986).

There are 3 established practices in CA to ensure validity of findings:

1. The *"next-turn proof procedure"* (Sidnell, 2013, p79): As Sacks described, in CA it is the data itself that provides our interpretation of talk: *"since it is the parties' understandings of prior turns' talk that is relevant to their construction of next turns, it is their understandings that are wanted for analysis"* (Sacks et al., 1974, p729). Hence, the analysis of an utterance is grounded in how participants in the interaction respond to that utterance. In this sense, the interpretation of an utterance is evident in the data presented, and this provides a transparency of analysis to the reader that enhances validity (Peräkylä, 2004).
2. Presentation of *"deviant cases"*: Regular patterns in talk can be demonstrated by presenting deviant cases. These cases, that are different from others in similar contexts or settings, can openly test hypotheses about the data: both in examinations of what the specific differences are, and how participants in the interaction respond to these differences. For example, questions requesting information place an obligation for the recipient to provide that information. Should the recipient not provide that information

(i.e. a deviant case), this is oriented to by the participants in the interaction – for example by the questioner further pursuing a response, or recipient apologising or stating that they do not know the answer. The participants, in accounting for why something has not happened as it should, themselves provide evidence for the ‘norm’.

3. Use of “*data sessions*”: Data sessions with CA researchers allow for repeated inspection and discussion of data (both with transcripts and the video recordings). This enables analysts an opportunity to reflect on observations and CA interpretations of action, sequence and turn design. Data sessions involve presentation of one or two examples of practices or actions, with analysis undertaken as a group to encourage discussion and debate. This allows public demonstration of individual analysis to other researchers, over many stages of the analytic process. At the beginning of the analysis, when only a minority of cases have been analysed individually, this can provide inspiration as how to approach the analysis of the remaining data. At later stages of the analysis, data sessions provided a forum for discussion that allow for re-characterisations of the findings from alternative explanations for behaviours from other analysts (Albert, 2014).

Recordings are at the heart of the CA method, preserving the important objects of study of communication: the practices that participants implement and are oriented to within temporal boundaries and sequences. Sacks (1984, :26) argued that recordings are “*a good enough record of what happened*” in order to analyse what in conversation is treated relevant by participants. However, as with all methods it is important to minimise potential biases. The presence of cameras may influence people's communication, or there may be something that the camera or the audio recorder does not catch and thus is not included in the analysis. High-quality recordings that control for these factors (for example by using un-intrusive equipment and logging when participants refer to the cameras) are thus very important: data collected using this method can preserve the details that the participants treat as relevant in interactions (Mondada, 2013).

CA, like all methodologies, also needs to recognise whether or not its findings can be generalised. However, CA embraces this within its analytic philosophy: communication is recognised as a complex object of study and blanket claims across contexts are not made (Parry and Land, 2013). While patterns can emerge and be described, the results of individual studies are not intended to be representative of the entire population. Despite this, as collections of certain types of data from different settings can be compared and certain patterns can be described as less context specific (Voutilainen and Ruusuvuori, 2010). Additionally, Peräkylä (2004, :37) also considers generalisability in CA as “*the possibilities of language use*”. While descriptions of talk by CA are not definitive descriptions of talk that *will* be used by a person in that context, they are descriptions of ways of speaking that *can* be used. In this sense, conversation analysts can identify possible ways that communication can be achieved in and across differing contexts.

### Quantitative Analysis

The frequency of certain features of the interaction, identified through CA, was counted and explored quantitatively. The presence or absence of certain practices or behaviours was entered into SPSS 22, and chi-square tests of independence (or Fischer’s or Monte Carlo tests where cell numbers were low) and independent samples t-tests were used to examine relationships in the data.

Statistical explorations of the data were designed to be secondary to the qualitative analysis. Practices in interaction are constantly shaped by ever-changing activities and contexts within interaction, and therefore while quantitative analysis can find relationships in the data, it must be recognised that these will be affected by any number of other interactional and contextual factors. Therefore, it was recognised prior to the start of the analysis that while statistical associations can be useful to “*assess the robustness*” of the qualitative conclusions (Peräkylä, 2005), the nature of interactions are such that they cannot prove or disprove qualitative findings (Schegloff, 1993).



### A note on the presentation of data

The data presented is in the form of transcripts containing Jeffersonian notation (Jefferson, 2004), details of which can be found in Appendix C. Data extracts were chosen in order to evidence the practice that was being described. Due to the unfolding and ever-changing nature of interaction, there were some examples that contained insertion sequences where participants would discuss something off topic, or where one of the participants would halt the progression of the talk to initiate repair. Of particular importance was that the extracts would be able to demonstrate the practice with maximum clarity to the reader, and thus shorter and more concise extracts were chosen for inclusion within the thesis. Additionally, care was taken to ensure that there was not too much repetition of the same doctors or patients in the examples chosen in order to add “*transparency and trustworthiness*” to the data (Tong et al., 2007, p356).

The doctor is represented as “DR”, the patient as “PT”, the companion as “CN”, and the nurse or support worker as “CC” (standing for ‘care coordinator’). The data is anonymous, and is labelled based on participant ID, with  $P_n$  (e.g. P01 etc.) standing for patient ID, and  $H_n$  (H01 etc.) standing for doctor ID. ‘H’ was used for DR ID because there were different healthcare professionals in the ShareD study, and ‘H’ was used for all. Where relevant, non-verbal behaviours will be indicated within the transcript in italic font. Important lines from the transcript as discussed in the text will have either the speaker initials or the key words in bold font.

The aims of this thesis focus on the responses of the person with dementia, the patient, rather than their companion. The companion is an integral part of the diagnosis delivery: from providing information for the doctor to make the diagnosis, having their own preconceptions about the patient’s behaviour and its causes, to being directly affected by the impact the condition has on their relative or friend and thus a key stakeholder in treatment decisions. However, the companion’s involvement in the interaction occurs in multiple, often extremely subtle, ways, which could be a thesis in its own right. Therefore, while the companion’s input is discussed when necessary for the analysis aims for this thesis, it will not be the focus of the findings.

## **Participant Information**

There were 81 video recordings of dementia diagnosis feedback meetings collected between May 2014 and October 2015 that were suitable for analysis. There are thus 81 patients in the sample, and 20 doctors.

### *Patient and Companion Sample Information*

The patient and companion socio-demographic information can be found in Table 4. The patients were on average 80 years old, ranging from 52 to 92. The 52 year old was the only patient under 65, with 48% (n=39) of the patients in their eighties. The majority of the patients were female (58%) and white (86%). Seventy per cent were born in the UK.

The scores on the ACE-III varied from 27-94 (average 67), and the score for the 12 patients who took the MMSE varied from 7-28 (average 21). The majority of the patients were therefore in the mild to moderate stages of dementia.

The majority of diagnoses being delivered were Alzheimer's disease (58%), with Vascular dementia (15%) and Mixed Alzheimer's and Vascular type (16%) being the next most common. For three of the patients the type of dementia was never specified. Some of the sample had rarer forms of dementia: three had Lewy Body dementia, two had Parkinson's dementia, and one semantic dementia. These patients, while having different symptom presentations than the more common dementias, did not have lower cognitive test scores. Those with the lowest cognitive test scores had either Alzheimer's or Vascular dementia.

That the majority of patients had the most common subtypes of dementia (i.e. Alzheimer's disease, vascular, and mixed dementia) was not surprising considering the consecutive sampling methods. That the majority of patients were over 65 reflected the fact that younger patients are likely to go through different pathways (e.g. neurology clinics) to be investigated for possible dementia. However, the overall sample contained a variety of subtypes, ages, and cognitive test scores. Should the lack of homogeneity may cause some

dementia diagnosis deliveries to differ from others, this was embraced as part of the CA method. As described above, should a lower cognitive test score or different dementia subtype affect the diagnostic communication, this can be described as a deviant case, which adds further to the description of a diagnostic 'norm' in memory clinics.

Companions were present in 93% of the meetings – there were 6 patients who attended the diagnostic feedback alone. Six patients brought 2 companions and 2 patients brought 3 companions. The majority (64%) of the companions were female. Companions were generally either children or children in law (45%) or the patient's spouse or partner (35%).

Forty-three of the patients were from Site A Devon Partnership Trust. Thirty-eight of the patients were from Site B NHS trusts: 11 from East London, 4 from Barts Health, and 23 from Camden and Islington.

#### Doctor Socio-demographic Information

Doctor socio-demographic information can be found in Table 5. Eleven of the doctors (55%) were from Site B and 9 (45%) were from Site A. They had worked an average of 12 years with people with dementia, ranging from 4 to 25. Fifty-five per cent were female and 80% white. The remaining 20% were Asian British or Indian.

There were an average of 4 patients per doctor (range 1-10). The doctors were primarily consultant psychiatrists (75%). Three (15%) were consultant geriatricians and two speciality doctors (10%).

<b>Patient Characteristics</b>	
Age	80 (52-92)
Gender:	
Female	47 (58%)
Male	34 (42%)
Ethnicity: (n=78)	
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%)
Country of Birth: (n=78)	
UK	57 (70%)
Other	21 (26%)
Diagnosis:	
Alzheimer's disease	47 (57%)
Vascular dementia	12 (15%)
Mixed dementia	13 (16%)
Parkinson's dementia	2 (3%)
Dementia unspecified	3 (4%)
Lewy body dementia	3 (4%)
Semantic dementia	1 (1%)
Cognitive Test Scores: (n=77)	
Addenbrooke's Cognitive Examination III (ACE-III) (n=64; total 100)	67 (27-94)*
Mini Mental Status Examination (MMSE) (n=12; total 30)	21 (7-28)
San Louis University Mental Status Examination (SLUMS) (n=1; total 30)	7
<b>Companion characteristics</b>	
Companion Present	75 (92%)
Two companions	6 (7%)
Three companions	2 (2%)
Gender:	
Female	53 (64%)
Male	30 (36%)
Relationship to patient:	
Child/Child in law	37 (45%)
Spouse/Partner	29 (35%)
Other	10 (12%)
Friend	3 (4%)
Sibling	3 (4%)

**Table 4: Patient and companion characteristics**

<b>Doctor Characteristics</b>	
Gender:	
Female	11 (55%)
Male	9 (45%)
Ethnicity:	
White British	13 (65%)
Other White Background	3 (15%)
Asian or Asian British	2 (10%)
Indian	2 (10%)
Clinician Type:	
Consultant Psychiatrist	15 (75%)
Consultant Geriatrician	3 (15%)
Specialty Doctor	2 (10%)
No of Years working in Dementia	12 (4-25)
Clinic Location:	
North London	6 (30%)
East London	5 (25%)
Devon	9 (45%)

**Table 5: Doctor Characteristics**

**Chapter Four:**  
**“Do you remember what this is all  
about today?”**  
**The Structure of Dementia  
Diagnosis Feedback Meetings**

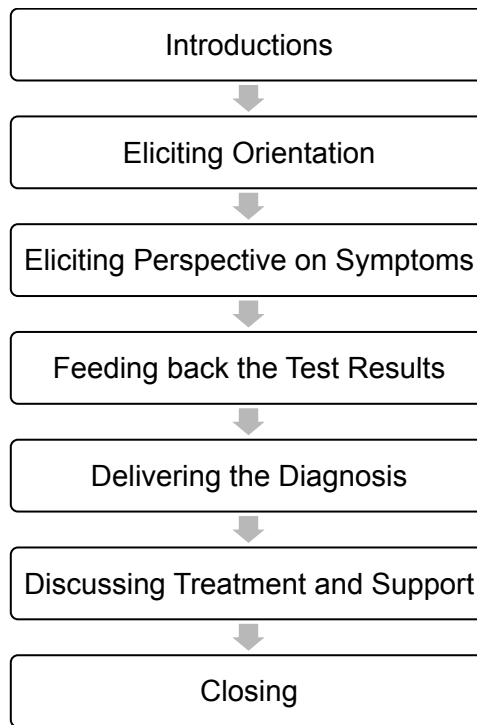
Doctor-patient interactions are one of many institutional interactions studied in CA, others including courtroom interactions, calls to emergency services, and classroom settings (Heritage and Clayman, 2010). One of the key features of institutional interactions is that there is an overall task to achieve within an organisational structure consisting of recurrent sections (Robinson, 2003a). This is easily identifiable in diagnostic feedback meetings. There is an overall goal – to inform patients of their diagnosis – and this goal is achieved through separate stages of the meeting, each with their own sub-goal. The stages prior to diagnosis delivery consist of different tasks that build up incrementally to the diagnosis delivery itself (Stivers, 2002). However, there are specific factors at play in dementia diagnostic interactions that can lead to differing trajectories in completing these tasks.

Given that the focus of this thesis is on the diagnosis delivery, this chapter will describe the stages of the meeting leading up to the delivery stage.

### **Stages of Diagnostic Feedback Meetings**

The institutional asymmetry evident in all medical interactions is present in dementia diagnosis feedback meetings. The doctor drives the interaction as the medical expert and steers the meeting through the different stages (Robinson, 2003a). As described in Chapter 3, much if not all of the information gathering and history taking on the patient's symptoms has been done prior to the diagnosis feedback meeting. Therefore the primary aim for the feedback meeting is to deliver the diagnosis and discuss treatment and support (National Institute for Clinical Excellence, 2006).

There are 7 stages that occur systematically in dementia diagnosis feedback meetings (see Figure 3 for an overview).



**Figure 3: Stages of dementia diagnosis feedback**

***Stage 1: Introductions***

In most of the meetings, the doctors are meeting the patients for the first time (n=61, 75%). Therefore, feedback meetings usually begin with the doctor introducing themselves and other medical professionals if present, and ensuring that they know the patient’s companion’s name and their relationship to the patient.

**(1) [P67\_H03]**

1 DR: hello: [            ther]e:  
 2 PT:                    [°(well/wow)°]  
 3            (.)  
 4 DR: hi::=>hehe< .hh [I- ] I'm: do:ctor (name) I'm the  
 5 PT:                    [hm,]  
 6 DR: consultant in the mem[ory ] cl[ini::c. ]  
 7 PT:                    [yeah.] [↑oh ri:ght]  
 8 DR: .hh ah: and I belie:ve you:'ve- [have met ]  
 9 PT:                    [yeah: I met]  
 10            [you before ] yeah.  
 11 CC: [>you met< me.]  
 12 CC: (na:[:me) >so] I'm< one of the nurses:..



13 PT: [yeah. ]  
 14 (.)  
 15 CC: °yeah.°  
 16 (0.6)  
 17 DR: [o::kay. ]  
 18 CN: [>°just putting that on°<] silent,  
 19 (.)  
 20 DR: .hh an:d an:d th- (.) this is your dau::ghter?  
 21 PT: yeah  
 22 (0.9)  
 23 PT: (na:me),  
 24 CN: [hi:: ]  
 25 DR: [hello:] there h(h) i

This stage is mostly short and straightforward as in the example above, and is evident as a typical introduction sequence (Pillet-Shore, 2011). The patient has just entered the room with her daughter, and something has happened on entry which has made her smile and caused her quiet exclamation (line 2) – it is unclear exactly what this is from the video. The doctor acknowledges this with a slight chuckle while he introduces himself with his name and role (lines 1-6). He then establishes the prior meeting between the patient and the nurse who did the initial assessment (line 8), which the patient and nurse both confirm (lines 9-11). The nurse states her name and role again, looking to the daughter while speaking (line 12). The patient’s daughter is looking at her phone and turning it to silent mode, which causes the slight delay in response (lines 14-19). The doctor then checks the patient-companion relationship (line 20), which the patient confirms and introduces her daughter by name (lines 21-23), and her daughter responding once she finishes putting her phone away (line 24).

Speakers choose to display specific category membership features in introductions, depending on what information is relevant to the recipient in that context (Pillet-Shore, 2008). The patient has met the nurse (who is present in the meeting) previously, and may be expected to be informed as to the nature of the appointment. Therefore, when the doctor uses the place reference “memory clinic” in introducing himself, thus referencing both the medical setting and the symptoms being discussed, he is displaying information that the patient

could be expected to already know. However, the patient's response – an upward intoned “oh right” (line 7), containing a ‘change of state token’ (Heritage, 1984) – indicates the information was not known to the patient. Additionally, the doctor's “I believe you've met” (line 8) invites confirmation from the patient that she has met the nurse before. If the patient had not confirmed this, it would also have been an indication of lack of orientation to the clinic process.

These aspects of the introduction stage are sufficiently similar to introductions in other settings that they may not be designed specifically as probes of patient orientation. However, the example above shows that apparent lack of awareness of the purpose of the meeting may become evident at this stage.

### Stage 2: Eliciting Orientation

The second stage of the meeting contains further, more explicit checks of patient orientation. Doctors often elicit patient understanding of the purpose of their meeting through direct questioning. How this unfolds is contingent on the patient's response.

#### **(2) [P46\_H50]**

1 DR: ri:ght (.) so, (0.8) so >do you know what?< (0.5) >do  
2 you remember what this is all about< today?  
3 (0.9)  
4 PT: er:: (0.6) no not really.  
5 DR: ah well I'll tell ya  
6 (1.0)  
7 DR: nh .hh (.) you came here  
8 PT: mm[m,]  
9 DR: [a ] while back  
10 PT: that's ri:ght [yes.]  
11 DR: [ ab]out your memory.

In this extract the doctor asks the patient if she remembers “what this is all about today” (lines 1-2). The repair from “know what”, to “remember what” shows doctor orientation to the fact that the patient may have forgotten rather than just not know the meeting purpose. This segment occurs at the beginning of the meeting, and thus the “this” clearly indexes the meeting itself, which is

reinforced by the doctor gesturing between them, non-verbally indicating the meeting. The yes/no interrogative format again invites an affirmative answer, but the patient answers with a dispreferred “no not really”, which comes with the delay and hesitation common in dispreferred responses (lines 3-4). The patient turns to her daughter and then back to the doctor while answering, which is a behavior that has been observed of people with dementia in medical interactions when they are struggling with providing relevant information (Jones et al., 2016). Her hedged answer – “not really” – is also likely to indicate a face saving strategy: it is expected as competent adults that we will not only know the reason for our medical appointments, but also be able to account for them (Heritage and Maynard, 2005). The doctor, in responding immediately and launching into a narrative describing what took place previously in the process, covers the patient’s loss of face in the interaction, while ensuring the patient orientation prior to progression onto the next stage of the meeting (lines 5-11).

The interaction unfolds differently when patients are aware of the reason for their presence at the clinic.

### (3) [P102\_H41]

1 DR: ↑what expectation did you have of coming here toda:y.  
 2 (1.5)  
 3 PT: somebody that would he:lp with my memory:,  
 4 DR: oh:: ↑ri:ght .hh ye::s [we:ll that's] what- that's what  
 5 PT: [kHHM ]  
 6 DR: we do::,  
 7 (.)  
 8 PT: mm::.  
 9 (0.8)  
 10 DR: .hh um tch (0.4) and I've heard the story:, er:: from::  
 11 the lady that spoke to your: daughter (name):;  
 12 (0.6)  
 13 DR: I >gather you have< ↑five children: is that ri[:ght?]  
 14 PT: [ ye:]s.

In this extract, the doctor asks the patient what she was expecting from the clinic (line 1). While there is some delay in the patient responding, she is able to

provide an answer that illustrates both the purpose of the clinic and some awareness of her memory problems (line 3). The doctor's upward intoned news receipt indicates the patient's answer may have been unexpected, but she continues with a confirmation of the patient's expectation (lines 4-6). The patient utters an emphasised downward intoned "mm", indicating acknowledgement and discouraging continuation of this topic (line 8) (Heath, 1992). The doctor is thus able to progress to the next phase of the meeting (lines 10-14).

The doctor will not always elicit orientation using a direct question, but instead will present the process prior to and/or the purpose of the meeting while inviting a response from the patient.

#### (4) [P85\_H24]

1 DR: so it's been a few months s[ince]  
 2 PT: [ YE:]S  
 3 (.)  
 4 DR: we saw you l[a:st]  
 5 PT: [ ye:]s  
 6 DR: back in September:  
 7 PT: y[es]  
 8 CN: [ m] h[m,]  
 9 DR: [we] saw you in this very bui:ldingz  
 10 PT: that's ri:ght.  
 11 (.)  
 12 DR: and I gather that (researcher name) has spoken to you::  
 13 [befor]e: you [came i]::n,  
 14 PT: [yes ] [yes ]

In this example the doctor is confirming with the patient their last meeting a few months prior. The patient comes in with an emphasised acknowledgement before the doctor finishes her first turn (lines 1-2), suggesting that he follows the projected action of her completing her description of their previous meeting, thus already indicating memory of that time. The doctor comes to a potential turn completion (line 4) and the patient again acknowledges her statement. The doctor however continues her turn, upgrading by adding a date reference to their prior meeting, and perhaps pursuing a more extended confirmation from

the patient that he recalls the meeting (line 6). The patient gives a slight nod in this turn and provides another acknowledgement token (line 7), with his wife also acknowledging this (line 8). The doctor continues with a final elaboration (line 9), upgrading again this time with a place reference and a questioning intonation, and the patient adds a stronger form of agreement in line 10. With this the doctor appears to accept that the patient remembers and is oriented to the diagnostic feedback meeting, and the discussion progresses to the patient's participation in the research project (line 12-14).

Similarly, patients can also show lack of orientation even when doctors do not explicitly question them.

### (5) [P182\_H49]

1 DR: I'm one of the:: psychiatrists.  
2 PT: ye:[:s=>you're the] psychi[atrist.<]  
3 DR: [yeah::, ] [.hh ] an:d (.) I just  
4 want to talk with you abou:t what we've done today:,  
5 PT: mm:,  
6 DR: .hh what we think might be going on and how: we can help  
7 you.  
8 (.)  
9 PT: .hh ↑oh.  
10 DR: is that al[ri::ght. ]  
11 PT: [>>well is there<<] more tablets,  
12 [=I take eight a day]: now  
13 DR: [ahh heh heh heh ]  
14 DR: I [know] I saw::!  
15 PT: [ah ]  
16 PT: [heh! heh!]  
17 DR: [.hh so, ] (.) in this clinic we see people with (1)  
18 possible: possible mild memory problems .hh and we try  
19 and deci:de (.) ↑is it due to: (.) getting olde[r,]  
20 PT: [oh]:.  
21 (.)  
22 DR: or: or could it be something else li:ke a dementia.  
23 (0.3)  
24 PT: well my wife has got dementia.=I think I told

25 [the other guy]  
26 DR: [ye:s, ]  
27 PT: and she's- and I: visit her:

The doctor finishes her introduction, and the patient repeats her utterance, which is a common feature of communication with people with dementia (Davis and Guendouzi, 2013) (lines 1-2). The doctor continues in overlap by stating the purpose of the meeting, including a reference to “what we think might be going on and how we can help you” (lines 3-7). This forecasting of a potential diagnosis with a suggestion the patient needs help may be the cause of the patient’s surprised response: with an upward intoned, emphasised “oh”, indicating that this is news to the patient (Heritage, 1984) (line 9). Given that the patient is from Site A, and would have had the brain scan and cognitive testing in the immediate 3 hours before this meeting, his surprise at the potential upcoming diagnosis may be unexpected. This may be why the doctor checks for his consent to this proposed plan for the meeting (line 10). The patient’s reply in overlap flags potential treatment as a concern: he’s taking eight tablets a day already (line 11-12). The patient’s eyes had been fixed towards the direction of the computer screen, which is displaying his brain scan, and when he looks at the doctor as he starts this utterance she begins to laugh. Doctor-initiated laughter is rare in medical interactions but has been shown to occur when doctors are faced with difficult interactional tasks, such as disagreement over causes of symptoms (McCabe et al., 2002, Haakana, 2001). It is therefore likely that this laughter is a result of the patient’s resistance to treatment.

The patient joins the laughter as the doctor aligns with the patient’s statement about multiple medications (lines 14-16). The doctor avoids answering the patient’s concern about medication by continuing her description of the purpose of the meeting. She gives a generalised clinic description (“we see people” line 16), and minimises the symptom profile of people who attend the clinic (“with possible mild memory problems” line 17-18), potentially as a result of the patient’s resistance. However, she adds specificity and thus stronger forecasting of the diagnosis – by stating the purpose as trying to distinguish between “getting older” and “something else like a dementia” (lines 19-22). It is unusual for doctors to explicitly mention dementia at this point in the meeting,

with 22 meetings (27%) containing mentions of 'dementia' prior to the diagnosis itself, and in 4 of these cases the term is raised by the patient or companion.

However, the reason for the explication of the dementia term becomes apparent in the patient's response, where he topicalises his wife with dementia who he visits in a home (line 24-27), and the doctor's emphasised acknowledgement of this (line 26) suggests prior knowledge. The patient does not however acknowledge the purpose of the meeting and the potential consequences as forecasted by the doctor, but continues with a description of his wife's condition once this extract ends. While this lack of acknowledgement may indicate a resistance on the part of the patient, it displays an orientation to the topics being discussed, which is demonstrated in the doctor not pursuing further demonstration of orientation, and instead engaging in the patient's description of his wife's behavior (not shown due to length of extract).

In summary, doctors in memory clinics can elicit patient orientation at the start of the meeting. This can be done through direct questioning or through stating the purpose of the meeting inviting patient acknowledgement. If the patient does not know the purpose of the meeting, the doctors will halt the progress of the meeting to ensure the purpose is made clear prior to continuing to the next stage. However, dementia terms are not often used in the meeting introduction.

### Stage 3: Eliciting Perspective on Symptoms

As mentioned previously, the doctor will already have a comprehensive report of the patient's symptoms from the assessment meeting. Additionally, the doctor will (mostly) have decided on the patient's diagnosis prior to the start of the diagnosis feedback meeting. However, doctors in memory clinics spend substantial time reviewing the information they have in their notes with the patient in the feedback meeting. While this may be expected in the clinics where there has been a gap of weeks or months between assessment and feedback (Site B) and thus further information may need to be gathered, this stage occurs as often in Site A meetings, where the information will have been gathered only an hour or two previously.

As stated above, 75% of the doctors have not done the history taking in the prior meeting, and therefore it may be that they are making some aspects of the report clear in this stage. However, it is evident that doctors are not simply collecting new or additional information regarding the patient's symptom history, but are primarily eliciting the patient's perspective on their illness.

### (6) [P79\_H17]

1 DR: ↑what I'm: (0.4) hea:ring from the repo:rt that my  
 2 colleague (name) wrote, (0.3) s:peaking with (companion  
 3 name) as we::ll (0.3) >is that< ever since your: husband  
 4 sadly:: (. ) ↓die::d, some years ago:, .hh  
 5 PT: three:: (. ) °yea[r:s.°]  
 6 DR: [ yes] you've ↑had >sort of< (0.5) some  
 7 difficultie::s that have come and go::;  
 8 (0.4)  
 9 DR: but when they've been there:: they've cau:sed you to  
 10 have problems with memory and concentration.  
 11 (0.4)  
 12 PT: oh: >well it'll< be: (1.8) whe:n something happens >or  
 13 anything< I:'m (0.8) I:=it's:: >ah-< I sort of  
 14 afterwards think oh I've lost my:: c(h)oo:l.=>y(h)ou  
 15 know er< (. ) [which wou]ldn't be:: (0.5) I wouldn't be::  
 16 DR: [↑ah ha. ]  
 17 PT: nasty or any[thi::ng ]  
 18 DR: [↑yeah: and] do you lose your cool more  
 19 easily:, these day:s.  
 20 (0.5)  
 21 PT: ↑no:: not really really

The doctor begins by accounting for his knowledge of the patient's history ("from what I've been hearing.." lines 1-4). The patient stakes her epistemic claim over her experience by specifying the amount of years that her husband has been dead for – from the doctor's "some" to "three" (lines 4-5). The doctor agrees and continues with his assessment of the patient's problems, pausing to invite agreement from the patient, which does not occur immediately (lines 6-11). When the patient responds she marks her answer as complex and avoids a straightforward agreement - beginning by registering the doctor's assessment



with the “oh”, and then launching into a ‘my side telling’ with “well” (lines 12-17) (Heritage, 2015). She does not align with the doctor’s description of her memory and concentration, but describes isolated incidents when “something happens” and she thinks “oh I’ve lost my cool”. The patient then minimises the severity of her difficulties, saying “I wouldn’t be nasty or anything bad”. The doctor’s response in overlap is an emphasised receipt of the patient’s description (“ah ha” line 16). He then continues his questioning using her wording – “do you lose your cool more easily these days?” (lines 18-19), thus building on the patient’s conception of her symptoms when approaching the diagnosis.

These exchanges are very similar to perspective display sequences described by Maynard in developmental disabilities clinics (Maynard, 2003a). The doctor firstly queries or invites the patient’s perspective (lines 1-10 above), the patient offers a reply or assessment (lines 12-15), and the doctor confirms this (lines 16, 18-19). However, difficulties can occur in memory clinic interactions where the doctor’s perspective invitation includes symptom descriptions that have been reported by the patient’s companions and not the patients themselves.

### (7) [P105\_H43]

1 DR: so:, (.) from >what I< understa::nd your memory problems  
2 started about nine months ago?  
3 (2.8)  
4 PT: ↑no °hha° I I've never said (.) that- >↑I've never said  
5 ↑↑that<  
6 DR: no: it's the: yeah:  
7 (0.3)  
8 PT: I've [never said fo-  
9 DR: [probably]  
10 DR: f- family mentioned that but in your (0.5) observation:,  
11 (.) how is your memory?  
12 (0.3)  
13 PT: ↑↑good  
14 (0.3)  
15 DR: >any problems?<  
16 (1)  
17 PT: only just recently when I lost my: (0.8) i- oh: my

The doctor references his knowledge of the patient's symptoms – “from what I understand” – without specifying the source of this knowledge (line 1-2). His question is in the form of a statement with a questioning intonation, projecting agreement from the patient. However, the patient does not answer for nearly 3 seconds – his eyes widen and he looks from side to side, before looking briefly at his daughter and then back to the doctor (line 3). He then disagrees strongly, challenging the doctor's formulation – repeating “I never said that” (line 4-8). He again looks at his daughter briefly on the second “I've never said” (line 4), potentially demonstrating a suspicion that she may have provided this information. The doctor immediately comes in with strong agreement, while smiling, again an indication of a delicate situation (McCabe et al., 2002). The doctor accounts for his knowledge: that he got the information from the patient's family (lines 6-10). He then changes tack and opts for a direct exploration of the patient's own perspective of his memory (lines 10-11). The patient, after a slight delay where he looks to the side and nods, states that it is “good” with a raised intonation, continuing the high pitch that indicates his disagreement.

The doctor does not respond directly to this answer, which is typical in cases where patient ‘good news’ reports of symptoms contradict the medical perspective (Beach, 2013). Instead, the doctor reformulates his query with a yes/no interrogative format - “any problems?” (line 15) (Raymond, 2003). This format of this question is similar to that commonly seen in history taking in primary care (Heritage, 2009). The use of “any”, which is a negative polarity item in question design (Heritage et al., 2007), requires the patient to account for providing a dispreferred “yes” response. This occurs after a second delay, where the patient does admit to losing his wallet (lines 16-18). However, he presents this as both a solitary occurrence and a recent one (“only just recently” line 17), thus remaining resistant to the doctor's initial formulation of “problems” over “nine months”.

In summary, doctors present their formulation of the patient's problem in order to elicit their perspective on their symptoms. Doctors can build on information provided by the patient in formulating the diagnosis in a way that is aligned with

the patient's narrative. However, as the assessment process involves taking the companion's view on the patient's symptoms separately from the patient, this can give rise to sensitive moments when doctors account for the information that has not been received directly from the patient.

#### Stage 4: Feeding back the Test Results

The majority of doctors feed back the results from both the brain scan and the cognitive testing. There is large variation in how much detail is given and how much time is spent on test feedback, as well as whether the cognitive test, brain scan, or both is fed back to the patient.

As is evident in other diagnostic interactions, the test feedback is designed to achieve intersubjective understanding of the consequences and thus set the patient's expectations for what is to come (Maynard, 2003a, Stivers, 1998).

#### **(8) [P145\_H49]**

1 DR: but what it shows us is that there's a little bit of  
2 shrinkage,  
3 (0.3) (PT nods)  
4 DR: which we do expect (.) as people get older: [.hh bu]t  
5 PT: [ye:s ]  
6 DR: I think there's perhaps a bit more in your brain  
7 (.) than I would expe[ct ]  
8 PT: [pect] ye[ah]  
9 DR: [ju]st due to your eighty  
10 four years  
11 PT: ye:s

The doctor in this example is discussing the brain scan results. She introduces the results as “what it shows us”, with the “it” referring to the brain scan (lines 1-2). This removes the doctor's agency in the news delivery, instead placing the ‘ownership’ of the results with the objective medical testing (Turowetz, 2015), a device often used in settings where resistance is common. The doctor describes “a little bit of shrinkage”, referring to the atrophy that often occurs in Alzheimer's disease, but not providing any more detail. Delivery of test results without interpretation places the patient in the role of ‘independent expert’, and

gives them the opportunity to demonstrate their understanding of the results (Pomerantz and Rintel, 2004). The patient passes up this opportunity and instead offers a non-verbal acknowledgement, suggesting a lack of knowledge of the consequences of the shrinkage (line 3). The doctor continues reporting the results, using the institutional “we” (Drew and Heritage, 1992), illustrating her knowledge as a medical professional, to say that this can be expected. The emphasised “do” and the extended “older” projects a “but”. This comes with an added specificity to the symptom description (“*your* brain” “*your* eighty four years”), and a change from the institutional “we” to the doctor’s personal reference of “I would expect” (line 4-7). This presentation of the test results alongside a meaning assessment that they cannot be explained by ageing is common in test feedback, and forecasts the cause as being a medical condition and thus a diagnosis being likely.

Many patients do not respond or respond very minimally to test feedback. However, patient responses can give doctors an indication as to their readiness for the diagnosis.

### (9) [P86\_H23]

1 DR: u:m, (.) doctor (name) did the:: (.) cognitive testing  
 2 with you:: (0.4) .hhh erm (.) there were some  
 3 significant problems in a couple of areas.  
 4 PT: °mm°  
 5 DR: specifically arou:nd memory: you were performing (.)  
 6 below (.) where we [would expect ]  
 7 PT: [°yeah I’m not°] I’m not too certain  
 8 about that because er (0.4) I: (0.4) hhh (0.6) I:, (.)  
 9 er (.) >you know< at my age I::, (0.4) and remembering  
 10 a lot and [I:: re- remember an awful lot of things.  
 11 DR: [yea::h ]  
 12 DR: .hhh (.) yes an- and tha:t is not surprising because  
 13 what we fi:nd is it’s (.) short term memory, (0.4) .hh  
 14 that’s, (.) dominantly affecte:d

The doctor is feeding back the cognitive test results (line 1-6). The feedback initially lacks specificity, using the generalised medical term for the

assessments (“cognitive testing”), and reporting “significant problems in a couple of areas”, but with no indication as to what these problems are. This is a more paternalistic format than the last extract, which did not explain what the results meant (“there’s a little bit of shrinkage” extract 8 lines 1-2), and thus invited patient interpretation (Pomerantz and Rintel, 2004). The patient in this example utters a quiet continuer (line 4), and the doctor specifies the findings – that the patient’s “memory” scores were “below where we would expect” (lines 5-6). The patient enters in overlap in with a direct challenge to the test results, demonstrating his experiential expertise of his symptoms (line 7). This is done with delicacy and respect for the doctor’s epistemic authority as a medical professional (Peräkylä, 2002). The litote “I’m not too certain” (line 7) makes the disagreement less direct. The patient then delivers a contrasting report of his abilities (lines 8-10), similar to how patients show resistance in primary care. He references his age, thus putting this forward as a cause of any difficulties he may be experiencing. He states that he remembers “an awful lot of things”, minimising the severity of his memory problems. The doctor acknowledges the patient’s perspective but encompasses it into her illness explanation (lines 12-14). She uses the institutional “we” in line 13, restating her medical authority while also removing the agency from herself. Her report of “short term memory that’s dominantly affected”, with the emphasised “short” illustrates that long term memory may well be intact. This provides an explanation as to why the patient may still be able to remember “an awful lot of things” and thus acknowledges, while also refuting, his view on his symptoms. Additionally, the use of “affected” insinuates that there is a disease that is causing the patient’s problems, and thus forecasts a potential diagnosis. However, this statement also assumes that the patient will understand that the purpose of the testing is primarily to uncover short term memory problems, as this is the most common symptom of early stage dementia. If the patient does not understand this, it does not address his opinion that he did not do badly on the test.

Given this strong forecasting that can accompany test result feedback, it may be expected that there would also be negative responses to the test results as patients may come to a distressing realisation that they will be receiving a diagnosis. However, this is rare in the data. The following extract is one of the very few examples of explicit negative patient response to test feedback.

**(10) [P23\_H21]**

1 DR: u um (.) an:d (.) you know we- do you remember we did a  
2 scan of your hea:d  
3 (0.3)  
4 PT: mm.  
5 (0.8)  
6 DR: >and it< showed that- your: (.) got quite a lot of  
7 shrinkage of your brai:n.  
8 (2) ***(PT pulls mouth downward and turns to wife)***  
9 PT: °°hm°°  
10 DR: mm:.  
11 (.) *(wife smiles at PT, PT smiles)*  
12 DR: .hh [which] i- i- [it might-]  
13 **PT:** [°hm° ] [not funny]  
14 (0.3)  
15 DR: er no: it's not really very funny [it's not it's] NOT a  
16 CN: [ha ha ha ]  
17 DR: good thing: to have but >we don't get any choices about  
18 what happens an[d< what's] happening to u:s [.HH]H u:m  
19 PT: [no. ]  
20 CN: [mm.]  
21 (0.3)  
22 DR: a:nd (0.5) what we would normally think=and it showed  
23 (0.3) that >you know< there's no tumours >and it<  
24 showed that you:'d ha:d (0.8) some ti:me a fall  
25 (0.4)

This example is from Site B so the patient will have had his brain scan months ago, which is likely why the doctor begins the scan feedback asking if he remembers the scan (lines 1-2). After a minimal answer from the patient (line 4), the doctor feeds back the results – “quite a lot of shrinkage” (line 6-7). The patient responds to this news by turning to his wife and pulling a face with a downward turned mouth (line 8). His wife does not immediately turn to the patient until the patient produces a small very quiet chuckle (line 9). She smiles at him as the doctor utters an emphasised acknowledgement (line 10). The doctor starts to continue her report of the test result, possibly about to state

what this means (line 12), when the patient produces an assessment of the results, stating it's "not funny" (line 13). This demonstrates an understanding that this "shrinkage" is likely to have negative consequences. The doctor agrees, and both the patient and his wife laugh (the patient silently, not shown on transcript, lines 15-16). Patient laughter has been shown to occur as a response to problematic situations (Haakana, 2001), and thus this joking is likely an illustration of understanding that this shrinkage on the scan is bad news. The doctor continues with a confirmation of the bad news but abandons further analysis ("what we would normally think" line 22) to try and reassure the patient, stating that there were "no tumours". She then shifts the topic to the patient's history of falls, moving on to a different aspect of the brain scan (lines 14-24). There were only 6 (7%) patients who provided negative assessments of the test results, while 13 patients (16%) make jokes at the test feedback stage.

The doctors are thus using the test results to illustrate that the patient has memory difficulties, and that there is a medical reason for these beyond old age. Patients can respond to test feedback with differing explanations for the results, attributing any difficulties to age or other reasons such as the type of questions or how the test was conducted. Very few patients explicitly indicate understanding of the negative consequences of the test feedback. If the patient shows resistance or offers different explanations for their difficulties, the doctor will re-state the illness explanation, often through emphasising their medical knowledge.

However, one difficulty in formulating dementia diagnoses is that, as explained previously, the test results do not in themselves indicate dementia, but are part of a body of evidence the doctors use to make a clinical judgment when making the diagnosis. Therefore, simply presenting the test results will not always be a sufficient method of forecasting the diagnosis to come. Additionally, patients are unlikely to have an understanding of the complexities involved in interpreting the test results. If the test feedback is not approached with these factors in mind, it can lead to confusion about the meaning of the results. The following extract (split into two parts) is an example of how this can cause difficulties of the progression of the test feedback to the diagnosis.

**(11) [P101\_H43 (part 1)]**

1 DR: now your: (.) memory te:st (.) that you did today:,  
2 (0.8) wasn't too ba:d,  
3 (0.7)  
4 DR: you got eighty three: out of a hundre:d  
5 (.)  
6 PT: ↑↑there you ↑are::,  
7 (0.9)  
8 DR: ↑now:  
9 (.)  
10 PT: °↑hooray:°  
11 (.)  
12 PT: ha thh  
13 (.)  
14 DR: >you know< looking at every[thi:ng I w I would ]  
15 PT: [(I'm not dementing )]  
16 DR: probably expect you to score slightly more:,  
17 (.)  
18 DR: so it's not a bad score:: but [I ] think your  
19 PT: [no]  
20 DR: memory is affected  
21 PT: .Hh  
22 DR: you clearly struggle with short term memory: ques[tions]  
23 PT: [mm ]  
24 hm,  
25 DR: a:lso naming questions so you're [ri]:ght tha:t  
26 PT: [m ]  
27 DR: forgetting na:mes etcetera is a problem,=it was  
28 [ev]ident,  
29 PT: [m ]  
30 (.)  
31 DR: on the ↑te:st.  
32 (.)  
33 DR: .hh the other thi:ngs were (0.3) your:: (.) visual (.)  
34 visuo orientation wasn't very good,  
35 (.)  
36 DR: so the drawing te:st you  
37 di[dn't, (.) you struggled a bi:t.]  
38 PT: [hhh (*smiling then shakes head*) ]





The doctor continues in the next extract, directly addressing the patient's attribution of her problems to old age, which she stated in the history reviewing stage.

**(12) [P101\_H43 (part 2)]**

45 DR: u::m  
46 (0.3)  
47 DR: now, (.) you a:sked me:: whether just your age?  
48 (0.3)  
49 DR: ↑probably no:t.  
50 (.)  
51 PT: °mm:°  
52 (.)  
53 DR: I would thi:nk (0.4) uh:: changes in your brain  
54 circulation;  
55 (0.3)  
56 DR: may play a par:t in this;  
57 PT: °mhm,°  
58 (.)  
59 DR: uh: although, (.) the scan doesn't show any shrinkage in  
60 the brai:n; which can happen in Al:zheimer's disease  
61 PT: ↑mm:  
62 (0.7)  
63 DR: the- the scan is normal on that fron:t,  
64 PT: ↑↑mm:  
65 DR: but ↑someti:mes there can be a sma:ll (.) shrinkage  
66 which may not >be visible on the< sca:n <which is often  
67 in> Alzheimer's disease.= [I do]n't think you ha:ve (0.8)  
68 PT: [mm. ]  
69 DR: °°a-°° primarily: (.) an Alzheimer's type ↑problem.  
70 (.)  
71 DR: he:re;  
72 (.)  
73 PT: ↑hm  
74 DR: but there: can be a sma::ll (.) element of that.  
75 PT: °mhm:.°

The patient responds minimally with a quiet continuer to the doctor's dismissal of her attribution of her difficulties to her age (line 45-52). Her body language remains reduced: sitting with her arms crossed. The doctor moves on to his explanation for the memory problems – “changes in your brain circulation can play a part in this” (lines 53-56). This projects an underlying physical problem as the cause of the patient's problems, most likely vascular dementia. However, the patient is unlikely to have heard of vascular dementia and thus this will not be a clear indication of the diagnosis to come. Additionally, the qualified language (“I *would* think...*may* play a part) indicates some uncertainty, and the doctor then reports that there is not any shrinkage on the brain scan “which can happen in Alzheimer's disease”. He re-emphasises this seemingly good news from the scan, saying it is “normal on that front”. The patient then changes the tone of her “mm” responses, with a higher pitch and a smile, indicating that she takes this for good news. However, the doctor continues with a qualification of this report, saying that it just “may not be visible”. He then immediately reaffirms his original positive statement (albeit in a qualified format) – that the patient does not have “primarily an Alzheimer type problem, but there can be a small element of that”.

The patient ends up receiving a diagnosis of mixed Alzheimer's and vascular dementia. With the knowledge of how doctors come to their diagnostic conclusions – that the most important aspects are the reports of memory impacting daily functioning and that borderline test results are used as part of clinical judgments – it is possible to see how the doctor is building this into the test feedback. However, the patient is a 90 year old woman who is unlikely to know that there are types of dementia that are not Alzheimer's disease, or that there may be no indication of Alzheimer's on the brain scan but a diagnosis of dementia may still be made. Therefore, in presenting the results in this way, the doctor has caused misunderstandings (as evident in the positive patient responses in lines 10, 15, 61, and 64 for example) that may be difficult to rectify when it comes to the diagnosis and treatment stage.

In summary, feeding back the test and scan results is an effective way for doctors to forecast the diagnosis, usually by emphasising the patient's problems are caused by something beyond ageing. Patients can show resistance and

negative responses to the test results, but mainly respond minimally. The fact that dementia is a diagnosis based on clinical judgment, not on the test results alone, can lead to test feedback causing patient misunderstandings.

The introduction, eliciting patient orientation, eliciting patient perspective, and test feedback stages are the 4 stages that lead up to the diagnosis delivery. The next stage – delivering the diagnosis – will be analysed and discussed in detail in the next two chapters. The final two stages are discussing treatment and support, and closing. A short overview of these three stages will now be presented, in order to present how the rest of the diagnostic feedback interaction usually unfolds.

#### *Stage 5: Delivering the Diagnosis*

This stage will be described and discussed in detail in the next two chapters of the thesis.

#### *Stage 6: Discussing Treatment and Support*

After the diagnosis has been delivered the meeting moves on to treatment options, with medication decisions for patients receiving a diagnosis of Alzheimer's disease or mixed dementia. Discussions also include arranging the next appointment with the team, social services support in the home, stopping driving, and planning for the future. This stage takes up the largest portion of the meeting, and the topics discussed vary according to the support available in different services and regions and the individual needs of the patient.

#### *Stage 7: Closing*

In the vast majority of the meetings the doctor gives a summary of what has been discussed and tells the patient they will receive a letter with all the information from the meeting. This can sometimes also include a negotiation as to whether the patient's companion also wants to receive the letter, and discussion of contact details for future appointments.

### Summary

There are 7 stages in dementia diagnosis feedback meetings in memory clinics, with 4 occurring prior to the diagnosis delivery stage. These 4 stages each contain sub-goals that are relevant to the diagnosis delivery. The introduction stage and the eliciting patient orientation stage appear to be aimed at seeing if the patient knows why they are at the meeting. The eliciting patient perspective and test feedback stages are aimed at seeing if the patient has insight into their cognitive impairment. The test feedback stage can also forecast the nature of the diagnostic news to come. The 4 stages thus enable doctors to establish the patient's orientation and insight, and rectify any difficulties that may occur through lack of awareness of the purpose of the meeting, or lack of agreement as to the nature of the patient's symptoms. The doctors thus work to ensure patient readiness for the diagnosis prior to the delivery.

### **Quantitative analysis**

The average length of diagnosis feedback meetings was 27 minutes and 59 seconds – ranging from approximately 8 minutes to 64 minutes. The frequencies of each stage of the meeting prior and including the diagnosis delivery stage, and the length of time taken in each, are reported in Table 6. The quantitative description of the Introduction stage (Stage 1) is not reported, as it was evident from the data that in many cases the introduction stage had either already occurred or had already started when the recordings began. Therefore, while there are 60 recordings that include the introduction, reporting this would be a misrepresentation of the regularity that doctors introduce themselves at the start of memory clinic diagnosis feedback meetings.

The diagnosis delivery stage was the only stage that occurred in all of the meetings, with the other stages present in over 80%. There was variety in the length of each stage, depending on the nature of what was being discussed. For example, the longest history review was over 26 minutes, but this included a long discussion of recent traumatic events that had occurred in the patient's family. While nearly all the meetings reported the test results, there was variation in whether both the scan and the cognitive test results were fed back

to the patient. Additionally, in some meetings the feedback of the testing would be extremely brief, for example *“and looking at the scan you went to this morning – the brain scan – that showed some shrinkage in the middle part of the brain”* (P50\_H43).

Stages	Number of meetings	Mean length in minutes (range)
Eliciting orientation	67 (83%)	0:57 (0:05-3:40)
History reviewing	69 (81%)	04:11 (0:15-26:30)
Test feedback	Cognitive test: 63 (78%) Brain scan: 64 (79%) Both: 59 (73%) Either: 78 (96%)	1:02 (0:10-5:10) 1:50 (0:05-13:15) 2:42 (0:20-18:25)
Diagnosis delivery	81 (100%)	2:39 (0:25-10:10)

**Table 6: Frequencies and lengths of stages**

The data shows that doctors place great importance on eliciting patient orientation and patient perspective on their symptoms at the start of meetings. Given that most doctors will have already decided on their diagnosis prior to feedback, it is likely that the purpose of eliciting this information is to inform how they should approach the diagnosis delivery and treatment discussions.

Of the 81 patients in the dataset, 50 (62%) demonstrated either a misunderstanding or different interpretation of the purpose of the diagnosis feedback meeting. Eighteen of these patients answered negatively to explicit questioning of their understanding of the meeting purpose in stage 2 of the meeting (e.g. *“do you know why you’re here?”*). The other 32 patients in this group gave alternate explanations for why they were seeing the doctor in one of the first two meeting stages, for example with statements like *“now I’m confused with all this going on, I came out this morning to find out about my medication”* (P150\_H41). Twelve patients answered explicit questions in stage 2 of the meeting, thus explicitly showing orientation to the meeting being about memory problems. The remaining 17 patients demonstrated orientation to the diagnosis

feedback with statements indicating knowledge of the prior stages of the process, for example by expressing a desire to find out the test results – *“I was really anxious to learn the results of the CT”* (P85\_H24).

Fifty-one patients (63%) displayed some lack of alignment with the doctors’ formulation of their symptoms in the stages prior to diagnosis delivery. This was demonstrated through patients offering other explanations for the test results in 28 of the meetings. The other 23 patients minimised the severity of their symptoms in the stage where doctors elicit the patient’s perspective by downplaying their experience of symptoms. This was often expressed by attributing difficulties to age – e.g. *“that’s not bad is it for an old woman?”* (P57\_H43). The remaining 30 patients demonstrated explicit concerns about their memory having got worse – e.g. *“my memory’s appalling...I’m worried, I think they’re all worried”* (P164\_H63).

In summary, the 4 stages prior to diagnosis delivery occur systematically across the meetings, with each stage occurring in at least 80% of the data. These stages are successful in eliciting patient orientation and insight, thus enabling doctors to be aware of this prior to delivering the diagnosis. Over 60% of patients are disoriented to the purpose of the diagnosis feedback meeting at the beginning of the meeting. Additionally, over 60% demonstrate a lack of insight into their symptoms severity, both when perspective was explored in the history reviewing stage, and in response to the test feedback.

## **Discussion**

The structure of the diagnostic feedback meetings reflects the complexity of the task needing to be accomplished: telling someone they have dementia. The structure has similarities to other diagnostic meetings, with discussions of the patient’s symptom history and presentation of the test results forecasting the nature of the diagnosis. However, it also contains differences from other medical settings, with doctors explicitly eliciting patient orientation at the start of the meeting. Additionally, doctors need to explicitly account for any knowledge they have of the patient’s prior symptom description due to the possibility this has been communicated by their companion, and present the test results with

strong forecasting to prevent misunderstandings. This is, in many ways, is a result of the memory clinic set-up, with initial assessments and brain scans occurring separately, and often with different clinicians, from the diagnosis feedback. However, it is evident from the data that the structure of the feedback meeting is also directly concerned with identifying potential differences between patient and doctor expectations concerning diagnosis feedback.

The focus on patient orientation is the primary feature of the structure of dementia diagnosis feedback meeting that makes it different from other settings. Patient disorientation or confusion as to the purpose of the meeting can be detected as early in the meeting as the introduction stage. Following this is a stage where orientation is explicitly elicited, either through direct questioning or through presentation of the memory clinic process inviting patient acknowledgement. Should the patient demonstrate confusion or lack of knowledge of the purpose of the meeting, doctors will re-state the meeting purpose. That nearly two thirds of patients in our dataset showed some level of disorientation to the purpose of the diagnosis feedback illustrates that it is a challenge that doctors in memory clinics are facing on a regular basis, one that they overcome by eliciting and establishing orientation before continuing with diagnosis feedback.

Given the nature of dementia and its effects on short term memory and concentration it may be unsurprising that doctors will need to remind people why they are at the memory clinic. However, patient confusion as to the purpose of the meeting should not automatically be attributed to potential cognitive impairment. As described in Chapter 3, the patient appointment letter will often not state explicitly that the memory clinic purpose is to assess a person for dementia. Only one of the clinics we collected data from reported systematically providing pre-diagnosis counseling for patients attending the memory clinic to manage expectations. Evidence from the literature describes GPs referring people to memory clinics without providing information on possible consequences or reasons for referring (Cahill et al., 2008).

Therefore, patient disorientation to what the meeting is for may not be due to cognitive impairment, but rather to a explanation from healthcare professionals



before the diagnosis feedback. This lack of explanation continued in how doctors orientated patients to the meeting purpose within the meeting itself. When introducing the purpose of the meetings, doctors rarely mention their function as finding out whether the patient has dementia. Patients and their companions mirror this by also rarely explicitly stating concerns about dementia prior to delivery. Instead, doctors, patients, and their companions are far more likely to use euphemistic terms such as “memory problems” or “forgetfulness”. When doctors explain the purpose of the meeting they will use these terms, most likely to ensure the patient knows what symptoms will be discussed. Additionally, they will often state that the meeting will include feeding back the test results. However, direct descriptions of the meeting specifically characterising it as dementia diagnosis feedback are rare. This suggests that orientation to the relevant symptoms (and not the possibility of dementia) may be all that is required by doctors at this stage of the meeting to ensure a smooth progression of the diagnostic interaction. However, this may not be an optimum strategy in terms of ensuring patient readiness and understanding.

Doctors are thus, while ensuring patients are oriented to the meeting purpose, still approaching the dementia diagnosis itself delicately prior to the diagnosis ‘proper’. This is likely to be a result of the related challenge of delivering a diagnosis – that of patient resistance. As discussed in the introduction, while there may be dementia-specific reasons for disagreeing with the doctor’s diagnostic formulation, there are other reasons that patients may resist their diagnosis that are also present in other diagnosis settings, for example denial, stigma, or alternative viewpoints as to the cause of their difficulties (Cheston, 2005, Clare et al., 2016). These can also be intertwined, as with mnesic neglect, where information that is threatening to the self is less likely to be remembered (Christopher and Cheston, 2015). It is thus not surprising that many of the strategies that were observed to occur in the memory clinic data are similar to that which has already been described in other settings. For example, Monzoni and Reuber found that doctors delivering non-epileptic seizure diagnoses also reviewed the history that had already been collected with patients (Monzoni et al., 2011b). Similar to the memory clinic data, the authors found that doctors used this information to then engage the patient in a two-way, ‘bilateral’, discussion to build up to the, potentially unexpected,

psychological explanation for their seizures. Gill and Maynard report similar activities in developmental disabilities settings, with doctors eliciting the parent's perspective prior to diagnosis delivery, which "*allows for persuasion*" should parents disagree on the nature of their child's difficulties (Gill and Maynard, 1995, :16). This practice is also similar to Stivers' description of pre-diagnostic commentary in veterinary settings, where vets forecast the diagnosis in the earlier stages of the meeting, which works to enable space for vets and pet-owners to negotiate treatment options (Stivers, 1998). That the memory clinic is another example of doctors using this strategy shows how using caution in approaching the diagnosis is an effective method of dealing with patient resistance, allowing room for manoeuvre prior to naming the illness.

Eliciting the patient's perspective is therefore primarily aimed at establishing the extent that patients are outwardly acknowledging their symptoms, and thus whether they may potentially display resistance to diagnosis, treatment, and support. This is likely to account for why despite doctor probing the patient's perspective, patient worries about their symptoms or consequences of the testing are rarely elicited. While patients may discuss family members with dementia, and thus demonstrate close experience with its consequences, doctors do not explore and patients rarely express how they feel about the possibility of having that diagnosis. While these aspects potentially could have been discussed in the initial assessment meeting, doctors do not allude to them in diagnosis feedback. It therefore appears that while gauging both orientation and acknowledgment of symptoms are demonstrated as important by doctors in the early stages of the meeting, gauging the emotional aspects of the patient's experience is not a priority. The avoidance of emotional aspects of diagnosis is consistent with what has been found in the literature, both in dementia (Zaleta and Carpenter, 2010, Werner et al., 2013) and other settings (Beach et al., 2005, Yoon et al., 2015).

The main stage of the meeting where patient concerns are expressed, although it does occur rarely, is the test feedback stage. The fact that it is more common for patients to make jokes in this stage than express explicitly negative responses is an illustration of how laughter is commonly used by patients in delicate situations such as negative test feedback (Haakana, 2001). Humour

was also identified in the literature review in Chapter 2 as a resource for people with dementia to save face when confronted with evidence of their cognitive impairment (Lindholm, 2008, Saunders, 1998b). Humour has also been described in the literature as a coping mechanism for both people with dementia (Wilson et al., 2007) and their companions (Buffum and Brod, 1998). It is therefore not surprising that humour is present in these meetings, and when it does occur it illustrates a likely expectation of bad news that has been forecasted by the test feedback, such as in extract 12 above.

As illustrated in neurology and developmental disabilities, as well as in cancer, HIV, and primary care, test results are a useful resource for doctors to forecast the diagnosis. However, a diagnosis of dementia involves a clinical judgment that, while backed up through the scan and the testing, is primarily formed using information from the patient's history. This can lead to confusing feedback, with seemingly high scores on the testing, or clear brain scan results, forecasting good news from a lay perspective but being used to forecast bad news by the doctor. Similarly, reporting the results of the testing indicating that the patient does not have Alzheimer's disease, but then going on to deliver a diagnosis of dementia (such as in extract 12) does occur, and can also lead to confusion. The fact that the different tests may have different forecasting uses depending on the nature of the results, may be the reason for the fact that while tests are fed back in nearly all meetings, there are many meetings where only one is reported. If the cognitive test is borderline but the scan shows signs of dementia, the scan may be discussed instead of the test, and vice versa.

It is important to note the impact of potentially confusing test feedback on patients. Studies of patient and companion experience of memory clinics name the testing process as one of the most anxiety-provoking aspects (Samsi et al., 2014, Robinson et al., 2011). Additionally, studies of people's interpretations of their dementia diagnoses illustrate that it is not only the naming of the dementia that affects how they view their condition, but the additional information that doctors do or do not provide will also have an effect and this will in turn affect how people engage with treatment and support (Clare, 2003, Byszewski et al., 2007). If doctors are not careful in explicating the reasoning behind certain

clinical judgments they can instead hinder patient orientation to and thus readiness for the diagnosis, such as in extracts 11 and 12 above.

It therefore appears that while the structure of the feedback meetings in memory clinics has developed to address the challenges of delivering a dementia diagnosis there are still difficulties evident in overcoming these challenges. Patient lack of orientation to the purpose of the meeting is common, with over 60% not oriented to the diagnosis feedback. However, when doctors orient patients to the purpose of the meeting, use of 'dementia' terms are rarely used. This delicacy in explicit descriptions of the purpose of the meeting could reflect concerns of causing distress or resistant reactions. This delicacy also accounts for doctors establishing patients' perspective on, and acknowledgment of, their symptoms prior to diagnosis, and then building upon these when approaching the delivery. Doctors will selectively choose aspects of the test results to feed back in order demonstrate the existence of symptoms when there is resistance, as well as forecast the nature of the diagnosis to come. However, the complex clinical judgments required to make a diagnosis of dementia can sometimes disrupt the forecasting if the results of the testing are not delivered with consistent assessments as to their meaning.



**Chapter Five:**  
**“We call that dementia”**  
**Delivery of the Dementia Diagnosis**

Contrary to findings in previous studies, all doctors explicitly named dementia when communicating with the patient and their companion (Dooley et al., 2015, Peel, 2015). While the length and complexity of the diagnosis delivery varies across the 81 feedback meetings, there are systematic patterns in how the diagnosis is approached. While the previous chapter described the overall structure of the diagnosis feedback meeting, the diagnosis delivery stage itself contains its own structure. The turns prior to and including the naming of dementia as the patient's diagnosis will be described in this chapter, and the response and ensuing turns will be described in Chapter 6.

### Identifying the Diagnosis Stage

Diagnosis delivery is interactionally marked as a separate phase of the dementia diagnostic feedback meeting, as found in other clinical settings (Byrne and Long, 1976, Heath, 1992, Stivers, 1998). As discussed in Chapter 4, the preceding phases included eliciting patient perspective on their symptoms and feedback of the test results. The diagnosis phase is often launched with some form of marker indicating an upshot from these discussions (Raymond, 2010), for example the lip smack and “so” in extract 1 (line 1), and the “now” in extract 2 (line 1).

#### (1) [P145\_H49]

1 DR: **tch so**, (1.2) the reason we see people in the memory  
2 clinic is that we're trying to work out whether or not  
3 they ha:ve (0.4) um a dementia

#### (2) [P178\_H63]

1 DR: **now:** in terms of a applying strict criteria for a  
2 diagnosis,

Given the strong forecasting that occurs in the previous stages (as discussed in the last chapter), and the recognised understanding from patients that results from testing will lead naturally to diagnosis, it could be reasonably assumed that patients may be expecting a diagnosis to be delivered at this stage (Robinson, 2003a). The design of these turns, placed after the test feedback and

containing upshot markers, signify the start of a new action within the meeting, that of the diagnosis delivery. There are usually a series of turns prior to the naming of the diagnosis itself, which appear to further mark the diagnosis as about to occur.

### **The Pre-Diagnosis Turns**

Diagnosis deliveries are similar to other news announcements in that they regularly occur over a series of turns of talk that are larger than just delivery and receipt (Maynard, 1997). News announcements are often occasioned by pre-announcements: turn sets prior to news deliveries where the speaker indicates to the recipient that the news announcement will be the next action (Maynard, 2003a, Terasaki, 1998). In Terasaki's seminal paper on pre-announcement sequences, she details how pre-announcements contain sequentially relevant features such as naming or a characterisation of the news, or requests/offers to tell the news, and are therefore "*presentation(s) of some news to come without therein providing that news*" (page 181). Pre-announcement first pair parts can be questions ("did you hear about X?") or statements ("you'll never guess what happened to me"), but require an adequate second pair part from the recipient (i.e. "no I didn't" or "what?") for progression to the announcement itself. Pre-announcements are thus the same as other pre-sequences in that they hearably are not discrete units in talk, and are "*integrally tied to the ensuing actions as their preliminaries*" (Schegloff, 2006).

Pre-announcements of this kind are extremely common in dementia diagnosis deliveries. However, they appear to have context-specific functions that identify them as a sub-type of pre-announcement, and will thus henceforth be referred to as pre-diagnoses (Spranz-Fogasy, 2014). Pre-diagnoses occur as pre-sequences to the diagnosis sequence, and exist as a formal structure designed by the doctor so that patients can anticipate that a diagnosis is immediately forthcoming within the meeting. They are therefore different from 'pre-diagnostic commentary', as described by Stivers, as they occur not as a method of showing reasoning in earlier stages of the meeting and thus forecasting the diagnosis to come, but as a direct indication the diagnosis stage has begun.



Furthermore, similar to other pre-sequences, pre-diagnosis sequences have a “*projective use*” (Schegloff, 2006) for the delivery itself. Pre-announcements are in the main oriented to assessing whether the news is in fact news to the recipient (due to delivering ‘already-known’ news being a dispreferred action) (Terasaki, 1998). However, while patients as recipients may suspect particular diagnoses, they do not have the medical expertise required to know their diagnosis for certain without the doctor’s input. Therefore, pre-diagnosis sequences appear to be designed to ensure a particular environment for the diagnosis delivery to occur.

There are 5 practices doctors use in the pre-diagnosis location. Four practices function as typical pre-sequences as described above. The first three examples appear to have the function of marking the diagnosis as imminent, thus ensuring the patient is oriented to the diagnosis being the next action. One practice appears to go further than simply projecting that the diagnosis will be in the next turn, and instead characterises the nature of dementia, naming it as the patient’s diagnosis. The final practice is different in nature, and contains an evaluation of the patient’s condition in the form of a diagnosis, but without naming the condition as a dementia (or type of dementia). Examples of these practices will be presented, along with examples of what occurs when patients block the progression from pre-diagnosis to diagnosis. Frequencies will be reported along with basic quantitative analysis to complement the qualitative findings.

### *Practices that mark the projected diagnosis*

The key feature of these practices is the explicit identification of the projected action – i.e. marking the diagnosis itself as the immediate next action. There are 3 ways that doctors design these turns to achieve this function.

#### *Asking for the patient’s consent*

The pre-diagnosis can entail offers or requests by the doctor to tell the diagnosis to the patient.

### **(3) [P62\_H03]**

1 DR: do you want to know what we:: (. ) what we’d ca:ll that



14 illegitimate.

15 (0.9)

16 PT: or a bastard or what ever you're called, (0.3) my nana  
 17 brought me u:p (0.5) a:nd er (.) now:, (.) I didn't  
 18 really have many frie:nds.

19 (0.4)

20 DR: okay. [well >what] we're talking about< now is (.) is

21 PT: [um ]

22 DR: you being here: in the memory clinic;

23 PT: yeah

24 (.)

25 DR: and this being a clinic appointment, (.) and I'm asking  
 26 you: if you would like to know what we think (0.3) the  
 27 problem is with your memory: and [your co]ncentration

28 PT: [yeah. ]

29 DR: .hh (.) and your ability to learn new things.=because  
 30 there is a problem there:.

31 PT: yeah.

32 (0.3)

33 DR: would you like to know what we think this is all (.) due  
 34 to:?

35 (1.4)

36 PT: well I've got this far: I mean I'm eighty-three.  
 37 (0.9)

38 PT: >I shouldn't< be on this earth very much longer in any  
 39 ca:se

40 (.)

41 PT: [>with a bit of< lu:ck]

42 DR: [I think you might ] be!

43 (0.7)

44 PT: ↓oh fhhh hh hh for heaven help you s(h)on!

45 CN: ah [ha ha ha ha ha ]

46 PT: [I love you to bits]

47 (0.6)

48 DR: ah [so is ] that a yes you would like to know: what we

49 CN: [uh huu]

50 DR: think this is due to?

51 PT: ye:s [okay:.]

52 DR: [you wo]uld okay

The doctor begins and then abandons what may have potentially been a consent question (line 1). She then chooses to state that “there are definite problems” with the patient’s memory, that there are “things” that have not been “working very well” (lines 1-5). The patient acknowledges this (line 4), but her utterance is extremely quiet and her eyes are closed in a long blink. She opens her eyes, and then her mouth slightly, when the doctor says “that” (line 3), and then her expression stays unchanging throughout the rest of the doctor’s turn and the following pause (line 6). The doctor then asks if the patient would like to know “what conclusions we’ve come to”, then reformats the question with a more specific “what this might be due to” (lines 7-11), with the “this” referring to the problems stated previously (lines 1-4).

The patient answers by offering a candidate explanation of her problems, referring to her difficult childhood (lines 13-18). This is evident as an inadequate response for the doctor to continue to the diagnosis delivery, as she instead responds by re-orienting the patient to the memory clinic (lines 20-22). The doctor re-iterates the previously discussed problems with her memory and concentration, and emphasises that “there is a problem there” (lines 25-30) with a questioning intonation, which the patient acknowledges (line 30). The doctor then re-states the previous consent question (line 32), and after a 1.4 second pause the patient provides another answer, again not confirming with the preferred “yes” response and thus again blocking the projected diagnosis delivery. However, this time the patient’s answer gives an indication that she may realise that a diagnosis is imminent, joking about being close to the end of her life (line 36-41). The doctor reassures her but the patient continues the joke, bringing her son and his wife into the interaction, and they join in the laughter (lines 44-46). When the laughter finishes there is a short pause and the doctor offers an interpretation of the patient’s answer and a stronger version of the consent question, asking “is that a yes you would like to know” (lines 48-50). The patient then answers in the affirmative, and both the patient and the doctor utter the shift-implicative “okay”, and proceed to the diagnosis (lines 51-52).

The consent question therefore references a cause for the patient’s symptoms and marks the diagnosis as the immediate next action by explicitly asking the

patient if they want to know their diagnosis. The question format requires an affirmative answer from the patient, which, if not immediately given, is pursued by the doctor before continuing to diagnosis delivery.

### *Eliciting the patient's perspective*

Another practice in the pre-diagnosis location is the perspective display elicitation. Gill and Maynard described doctors implementing perspective display sequences in developmental disabilities clinics, where doctors elicit the person's viewpoint on a potential diagnosis prior to delivery as a method of forecasting the news (Gill and Maynard, 1995). As discussed in the previous chapter, these types of questions are often present in the earlier stages of the meeting, but those in the pre-diagnosis location take two main forms. In some cases, doctors appear to be questioning the patient's memory specifically of prior discussions with clinicians of dementia as a potential diagnosis. In the following extract the doctor finishes feeding back the brain scan results before asking if the patient remembers her previous appointment.

#### **(5) [P31\_H21]**

1 DR: and it sho:ws a bit of shrinkage all o[ver,]  
2 PT: [ (?) ] yeah,  
3 DR: and that's probably what's causing your memory:  
4 PT: °mm°  
5 (0.4)  
6 DR: um, (0.6) >and I< think, (.) >I think< the other doctor  
7 talked about that but I don't know if you remember tha:t  
8 PT: no  
9 DR: oka:y (.) so we think that you have a <dementia:,>  
10 (0.6)

The doctor finishes the report of the findings from the brain scan, strongly forecasting a diagnosis (line 1-3). After a very quiet continuer from the patient, she then elicits the patient's memory of a meeting she had previously with another clinician (lines 6-7). While we do not know what this previous discussion included, the "I think the other doctor talked about that", refers back to the shrinkage from the scan as "what's causing your memory". In this site the scan would have been conducted after the patient saw the "other doctor" for the

initial assessment some weeks or months previously. Therefore it is likely that a possible diagnosis would have been discussed in the context of the brain scan referral, and also possible that this was named as dementia. The doctor's statement "I don't know if you remember that" is no preferring, thus showing her expectation that the patient has probably forgotten the prior discussion with another doctor. When the patient confirms this in line 8, the doctor continues with the diagnosis delivery (line 9).

Doctors also use more traditional perspective display format in the pre-diagnosis location – asking the patient for any preconceptions as to the cause of their symptoms.

### (6) [P34\_H23]

1 DR: tell me (.) are you conce:rned that your memory problems  
2 might be due to anything in particular  
3 (0.6)  
4 DR: are you worried about anything (.) [any] diagnosis  
5 PT: [°no°]  
6 PT: °no:° (0.8) no: I mean, (0.4) I'm worried about my (?)  
7 [(?) ]  
8 DR: [I kno:w ] (0.4) I know I know  
9 (0.4)  
10 PT: um, (.) I'm worried about my (0.4) my children  
11 [(?) ]  
12 DR: [I know]  
13 PT: my [wife.]  
14 DR: [but ] (.) but, (.) but are you worried about:  
15 memory are you worried that it [migh]t be::  
16 PT: [yeah]  
17 PT: I mean I'm merely old.  
18 DR: ri::ght  
19 PT: (?) the family  
20 DR: yea:h  
21 PT: my wife, (0.4) (grandson)  
22 DR: mm  
23 PT: and (.) I'm misunderstanding  
24 DR: mm:::

25 PT: #I':m (.) sometimes I# (.) misunderstand  
 26 DR: yea:h  
 27 PT: questions  
 28 DR: kuh kuh okay.  
 29 (0.8)  
 30 DR: and you want me to talk to you about the diagnosis yes?

The doctor in lines 1-2 elicits the patient's expectations as to a diagnosis – if his symptoms are “due to anything in particular”. While some of the patient's answer is unclear (he has had a stroke which has affected his speech), he answers in the negative (line 6), and instead states concerns about his family (lines 10 and 13). When the doctor reformulates the question in lines 14-15, the patient displays his candidate explanation for his symptoms, that he is “merely old”. While his speech again is unclear, he talks about his family and then states that he's aware that he can “misunderstand questions” (lines 19-27). The doctor receipts this description with an “okay” (line 28), and moves on to a consent question prior to delivering the diagnosis (line 30).

This extract illustrates that while perspective display sequences are pre-diagnosis sequences in that they mark the diagnosis as imminent, they rarely occur on their own in this environment as a pre-diagnosis practice. In all the examples the patient will either display a lack of memory of the previous discussion of dementia (like extract 5), or not display an expectation that they might be about to receive a diagnosis (extract 6). This thus blocks the progression to the diagnosis itself, and another practice is used to solicit an adequate go-ahead to continue to the diagnosis.

### *Statement of the purpose and process of the memory clinic*

The final pre-diagnosis practice in this group is a statement the purpose of the meeting in the pre-diagnosis location, highlighting the need to make a diagnosis and thus making relevant it the relevant immediate next action.

### **(7) [P90\_H24]**

1 DR: .hh so: I ↑think (0.8) .hh tch uhm what we have to do:  
 2 today is to (.) put together (0.6) three things.=we have

3 to put together the history of the memory problems:: (PT  
4 nods) as you described so we:ll;  
5 (0.5) (PT nods)  
6 DR: the: scan resu:lt;  
7 (0.3) (PT nods)  
8 DR: and the results of the (.) memory testing that we've  
9 done,  
10 (.) (PT nods)  
11 PT: ri:ght.  
12 DR: and we have to:: (0.3) think of what most what might  
13 be the most likely diagnosis.=or the most like[ly ]  
14 PT: (PT nodding) [ri:ght.]  
15 (0.3)  
16 DR: explanation for why you're having these memory problems  
17 PT: r[ight.] (nodding)  
18 DR: [over ] over the last four or five years  
19 PT: right.  
20 DR: and given that your scan hasn't shown any changes in the  
21 blood vesse:ls or an[ything li]ke that (.) .hh I  
22 PT: [right (nods)]  
23 DR: think the most likely diagnosis is that you've- got an  
24 early (.) Alzheimer's dementia:,  
25 (0.3)

The doctor in this extract begins with an in-breath and the upshot-marker “so”, and then presents the clinic purpose as “what we have to do today” (line 1). She then lists the “three things” that are required for a dementia diagnosis, and have been discussed in the preceding stages of the meeting. The doctor pauses after naming each of these pieces of evidence (lines 5, 7, and 10), and the patient nods at each pause. The doctor has reached the end of her list by line 9, and the patient adds a verbal acknowledgement token – “right” (line 11). The doctor, having got recognition of each of these pieces of evidence from the patient, finishes her description of the purpose of the clinic (lines 12-18). She uses the institutional “we”, marking her status as a medical professional, and that she needs to “think of” “the most likely diagnosis” or “explanation”. This statement of a cause of the problems makes the diagnosis the next relevant action. The



patient gives another minimal acknowledgement (line 19), which the doctor takes as a go-ahead to continue with the diagnosis (lines 20-24).

These descriptions of the meeting purpose often occur in conjunction with other pre-diagnosis practices, for example prior to the consent question. Many doctors use more than one pre-diagnosis practice, often in reaction to a block of the progression to the diagnosis delivery, as described above, but also often when patients only provide a minimal response. There are two further practices that are often used in conjunction with the three described, that appear to have different functions from simply marking the diagnosis as the next action.

### Practice to characterise the projected diagnosis

One pre-diagnosis practice aims to characterise the nature of the projected diagnosis prior to delivery.

### *Characterising dementia*

Doctors sometimes deliver a characterisation of dementia in the pre-diagnosis location.

### **(8) [P34\_H23]**

1 DR: °mm° just putting:: the: sca:n together with (0.3) u:m  
2 the findings: .hh HH HH >sorry< the commonest cau:se  
3 for: dementia (0.4) in this country: is a condition  
4 called Alzheimer's disea:se  
5 PT: yes:.  
6 (0.8)  
7 DR: now:: we can never make make that diagnosis with a  
8 hundred per cent certainty,  
9 (.)  
10 DR: >because the only way of doing that is £looking at the  
11 brain under a microscope£<  
12 (.)  
13 PT: ye:s.  
14 (.)  
15 DR: u::m (.) but we: try and: identify this condition as  
16 early as we ca:n,

17 (0.5)

18 DR: because there is some: medication that we can offer

19 people

20 (0.3)

21 DR: which ca::n (.) slow down the progression of this

22 condition.

23 (0.3)

24 DR: .hh tch (.) the medication is something ca::lled

25 donepezil or Aricept is it's other name,

26 (1.3)

27 DR: it doesn't work for everyone

28 (.)

29 DR: it probably works for:: °up to° sixty per cent of people

30 that take it, (0.4) but the only way <that we know>

31 >whether it's going to work for someone or not< is for

32 them to have a try with the medication.

33 (.)

34 PT: yes: yes.

35 (.)

36 DR: tch .hh so I think just putting >all of this

37 together=the most< (.) .h common °th-° the most likely

38 diagnosi:s (0.6) u:m for your memory lo:ss is (.) early

39 Alzheimer's disease?

40 (0.7)

41 PT: yea:h,

The doctor initiates the diagnosis phase by beginning to re-state the evidence, but she coughs, apologises, and then abandons this to name Alzheimer's disease as "the commonest cause for dementia" (lines 1-4). The doctor and patient have met before, and at the start of the meeting there is a reference to a discussion at their last meeting on the possibility of receiving a diagnosis of dementia, which explains why this is an explanation of Alzheimer's as a subtype rather than the umbrella term dementia. The patient acknowledges this explanation (line 5). The doctor makes explicit the uncertainty involved in the diagnostic process (lines 7-11), which the patient acknowledges after a small delay (lines 12-13). The doctor then indicates that the main function of making a diagnosis of Alzheimer's disease is for people to start taking the medication,

stating that while the medication is not effective for everyone it is important for patients to “have a try” (15-32). This definition strongly forecasts that the diagnosis is the relevant next action by topicalising both the process involved in making the diagnosis and the outcome of a diagnosis, i.e. treatment with medication. That this practice marks the diagnosis as the next stage is evidenced by the slightly impatient nature of the patient’s “yes yes” (line 32) (Heritage), after which doctor the continues to deliver the diagnosis (lines 34-36).

However, this practice provides a specific characterisation of dementia beyond just forecasting it as the imminent diagnosis. The doctor, in downplaying the certainty of the diagnosis and emphasising the medication, characterises the diagnosis in a way that minimises the impact of the diagnosis before delivery. These characterisations of dementia can be quite lengthy, and there is only one case in the data where the patient does not acknowledge the characterisation and solicit a move by the doctor to progress to the diagnosis delivery. Characterising dementia in the pre-diagnosis location therefore appears to be a powerful mechanism to obtain a go-ahead from the patient to deliver the diagnosis.

#### *Practice as a diagnostic assessment*

This practice is different from the previous group in that it is designed as a diagnostic turn – i.e. an evaluation of the patient’s symptoms as being caused by a medical condition (Heritage and Maynard, 2005). This works as a strong forecasting of the diagnosis to come in the proximate turn, but differs from the first group of practices in its structure and expectation of patient response.

#### *Statement of a “Problem” with a “Cause”*

This practice contains an assessment that the patient’s “problem” has a medical cause, but does not contain the diagnostic label.

#### **(9) [P164\_H63]**

```
1 DR: .hh so your scan means that there is (0.3) significant
2      (0.4) >sort of< you know damage to the brain >because of
```

3 the< (0.3) the vascular changes.=the blood circulation  
4 isn't as efficient a:s it once used to be perhaps when  
5 you were in your twenties and forties  
6 (.) (PT half nod and flexes hand)  
7 DR: .hhh um (.) .hh and- in my view: (.) that is what is  
8 causing your me- memory problems.  
9 (.) (PT small nod, CN small nod)  
10 DR: .hh and, (0.9) a:nd, (.) m- the name we use for this  
11 (.) condition is ca:llled (.) vascular: (.) dementia.  
12 (0.8) (PT nods and blinks)

The doctor in this example has been describing the brain scan results for just over 2 minutes, before producing the in-breath and upshot marker “so” (line 1), giving a summary of the results. These include “significant” changes, where the blood circulation “isn’t as efficient as it once used to be” (lines 1-5). With the use of “that” in line 7, the doctor then indexes these physical signs as “what is causing your memory problems” (lines 7-8). The doctor has thus definitively stated that there are “memory problems” that have a cause. This topicalisation of a cause, without giving a name to a condition, projects the next action as naming the cause, i.e., the diagnosis. The patient responds with a non-verbal continuer (line 9), and the doctor delivers the diagnosis of vascular dementia (lines 10-11).

Doctors will thus state the existence of problems with a medical cause in the pre-diagnosis location. These statements contain the structure of a news announcement, which, in a news delivery sequence, would be the base sequence and not thus not a pre-sequence in the strictest terms (Schegloff, 2007). In this sense, this practice is different from the prior practices, as the news announcement format places a different requirement on the patient to respond. However, this practice always occurs in the pre-diagnosis location: that is, before the utterance where “the patient’s problem is described as a medical category” (Peräkylä, 2005, p220).

A further indication of the pre-diagnosis nature of these statements is that the data demonstrates that both doctors and patients are oriented to the fact that the naming of the diagnosis is the likely next action. Patients typically respond

minimally, with continuers, as in the example above. However, patients can also challenge the doctor's evaluation of their problem, which halts the progression to the diagnosis delivery.

**(10) [P117\_H40]**

1 DR: um (0.3) and so: .h (0.6) the fact that there's more  
2 atrophy here: than in other parts of the brai:n .hh  
3 PT: m  
4 DR: um: (.) would (0.5) u u support a diagnosis of (.) >you  
5 know< a problem in the brain causing the memory problem,  
6 (.) that that we're (.) that we're measuring on these  
7 tests:.  
8 (.)  
9 PT: and (.) is thi:s (0.5) a serious problem?  
10 (.)  
11 PT: .hh u:m (.) for me: at the moment I would not think  
12 (1.1) that my memory is so bad that I would forget (0.4)  
13 lots and lots of thin:gs it's usually: °m°  
14 (0.6)  
15 DR: yea:h [so]  
16 PT: [sm]all things [not ] you know:: (.) rather  
17 DR: [I th-]  
18 PT: than::  
19 DR: I think you're right (.) an:d what (.) you know we would  
20 call this a you know (.) >it's certainly at< the (.)  
21 mi:ld or early end of (.) the spectrum of of  
22 [ mem]ory problems.  
23 PT: [yeahç]  
24 DR: .hh (.) and (*PT leans slightly towards DR and tilts*  
25 *head*) (.) the the commonest cause for a a a a a scan  
26 like this and the: memory (.) er difficulties that we're  
27 measuring on the test (0.3) the commonest cause for that  
28 would be something (0.4) called Alzheimer's disease.  
29 (.)  
30 DR: .hh and I suspect that's probably what's going on.  
31 PT: that I'm starting Alzheimer's  
32 DR: yeah  
33 PT: that's horrendous.

Similar to extract 9, the doctor has just finished showing the patient her brain scan results, and begins the diagnosis phase with an upshot marker before telling the patient that the scan results “would support a diagnosis of you know a problem in the brain causing the memory problem” (lines 1-5). This statement strongly projects a diagnosis as the next action in the use of the word “diagnosis”, but also again introduces the “problem in the brain” as the cause of the “memory problem”. It is also worth noting that the “memory problem” is also classified as something “that we’re measuring on these tests” (lines 6-7). The cognitive test results had also already been discussed, so the doctor is re-referencing both the scan and cognitive test results to account for the diagnosis. The repeated statement of the evidence from the testing within the pre-diagnosis sequence may be a result of prior resistance (Peräkylä, 1998).

The patient’s response to this pre-diagnostic statement is in the form of a question about the severity (line 9). She then expresses resistance to the doctor’s formulation of a “problem” with a “cause”, minimising her difficulties (lines 11-13). Her response blocks the diagnosis as the next action, describing her symptoms as not “so bad”, and that she just forgets “small things”, something that is common in older age and thus would not support a medical diagnosis. This re-description of her symptoms as a form of resistance, while not questioning the validity of the evidence, is similar to resistance to diagnoses in primary care (Peräkylä, 2002), and is thus recognisable as a block of the doctor’s progression to the diagnosis.

It is the doctor’s response to this block, and carefully executed progression to the diagnosis itself, that indicates his orientation to the naming of the diagnosis to be the necessary next action. The doctor, patient, and her husband have all been looking at the brain scan on the computer screen prior to this sequence, with the doctor turning to the patient in line 4. The patient however is still looking at the computer screen when she asks this question in line 9, and the doctor delays answering but moves his entire body and chair away from the computer screen and towards the patient. The patient continues after a micro-pause (line 10), describing the reasoning behind her question (lines 11-16). The doctor puts down his pen and nods along with the patient’s descriptions of

her problem, but interrupts as she pauses (lines 13-14), and comes in in overlap (lines 15-16). The patient then eventually turns from the computer screen to the doctor after she says “not” (line 16), and the doctor takes this opportunity to continue with his presentation of her “problem” (lines 17-19). In starting his turn with the phrase “we would call this a..”, he is indicating that there is a “this” that has a name, and thus seeming to start to deliver a diagnosis. However, he abandons this, and repeats the pre-diagnosis practice, evaluating the problem (“it”) as being “at the mild or early end of the spectrum of memory problems”. His emphasis of the “mild” and “early” (line 18-19) downgrades his previous description of “memory problems” (line 5) towards the patient’s description of her symptoms not being “so bad” (line 11). The patient this time utters a “yeah” (line 20), but the fact it is in overlap with the “memory problems” means that there is some uncertainty as to whether this is a go-ahead for the delivery itself. This may account for the doctor’s hesitancy (line 21), but the patient leans towards the doctor and tilts her head, indicating reciprocity for what is to follow. The doctor therefore continues and delivers the diagnosis of Alzheimer’s disease, which the patient responds to with a strong negative assessment (lines 21-33).

This example strongly demonstrates doctor and patient orientation that this pre-diagnosis statement is not a completed news delivery. The patient resists the doctor’s evaluation of her problems in the pre-diagnosis form, and the doctor downgrades this. This downgrade appears to be aiming to minimise the patient’s resistance prior to naming the condition as Alzheimer’s disease. The patient’s gesture towards the doctor after this downgrade, soliciting more information, also indicates an expectation of more diagnostic news. The difference in the patient’s reaction to the diagnosis naming than the pre-diagnosis also illustrates that the patient also orients to the delivery turn itself as the news announcement. However, it is worth noting that patient responses to diagnosis are not usually this extended, and this will be discussed in more detail in the next chapter.

### *Summary*

In summary, the doctors often start the diagnosis stage with one, or a combination of multiple, practices in the pre-diagnosis location. There are 5

practice types evident in the data. Three of these appear to primarily function to mark the diagnosis as the next action, orienting the patient to the diagnosis stage. A different form of pre-diagnosis practice is to characterise dementia prior to delivering the patient’s diagnosis, often downgrading its severity and highlighting the importance of treatment. Another practice doctors use is to explicitly evaluate the patient’s problem as being caused by a medical condition, thus providing a strong forecasting of the diagnosis as the next action without naming the dementia.

*Frequencies of the Pre-diagnosis Turns*

Table 7 illustrates the frequencies of the different pre-diagnosis turns described above, as well as how many of these were deployed prior to the diagnosis being delivered. In 83% of meetings doctors utilise the pre-diagnosis space, implementing at least one of the 5 practices. Clinicians will often use more than one method of prefacing the diagnosis when patients block the move from the pre-diagnosis to the diagnosis, either through not providing a response or showing non-alignment. In 38% of the meetings doctors use 2 or more of these practices, showing that patient non-alignment with the pre-diagnosis is common. In 11% of the meetings 3 or 4 pre-diagnosis practices are used before delivering the diagnosis.

<b>Practice</b>	<b>Frequency</b>
Statement of the purpose and process of the memory clinic	11 (13%)
Asking for the patient’s consent	20 (25%)
Eliciting the patient’s perspective	11 (13%)
Characterising dementia	17 (21%)
Statement of a “problem” with a “cause”	31 (38%)
<b>Number of practices used:</b>	
0: 22 (27%)	
1: 31 (37%)	
2: 21 (26%)	
3: 5 (6%)	
4: 3 (4%)	

**Table 7: Pre-diagnosis frequencies**



## The Diagnosis Delivery

The diagnosis delivery was identified as the turn in which dementia is first named as the cause of the patient's symptoms.

As with all aspects of talk, dementia diagnosis deliveries are not straightforward applications of the diagnostic label, but are designed in order to have a particular impression on the patient as the recipient (Sacks et al., 1974). It is evident from the data that the doctors are naming dementia as the patient's diagnosis in a way that both minimises the negative impact of the diagnosis and works against possible resistance. However, there is also evidence that doctors are aiming to enhance patient understanding that they are receiving a dementia diagnosis. There are four primary methods that the doctors use within the diagnosis turn: introducing dementia as a medical label, minimising the severity of dementia, re-referencing the evidence for the diagnosis, and choosing to present the diagnosis directly or through inference.

### 1. Introducing dementia as a medical label

#### **(10) [P154\_H41]**

```
1 DR: we think that what you've got is a: condition ca:lled
2     (.) Alzheimer's di[sea:se.]
3 PT:                                     [ah::: ]
4     (.)
5 PT: ↑ri:ght.
```

Many doctors classify dementia as a medical condition within the diagnostic turn – using terms such as “condition” (line 1) or “illness”. This is a common feature of the deliveries and defines dementia as a medical label, and therefore an area where the doctor holds epistemic authority. Should the patient or their family have beliefs about dementia, this introduction of the label as being something within the doctor's domain as a medical professional can allow the doctor to present the diagnosis differently to their preconceptions. This can work against negative responses to diagnosis – so building towards a portrayal of dementia as something different from what people might have read about in the

media or seen people they know experience. Additionally, if the patient sees their problems as attributable to old age, the emphasis of the “condition” demonstrates that there is a medical cause, and thus this labelling within the delivery can also manage potential resistance.

## 2. Minimising the diagnosis severity

### **(12) [P35\_H22]**

1 DR: um (0.4) so (.) I think (0.6) um (0.6) that that what's  
2 causing this problem is the **very very early stages** of a  
3 **condition called** Alzheimer's disea:se  
4 PT: °mm:°

The second feature of dementia diagnosis deliveries is the minimisation of the severity of dementia. This is evident in extract 12, where the doctor emphasises “the very very early stages” of the Alzheimer’s disease. The patient in extract 12 has an ACE-III cognitive test score of 60, which is 22 points below the cut-off for making a diagnosis. Although test results are not the sole criterion for measuring severity, this suggests she is not in the early stages of the condition. Additionally, statistical analysis showed no link between cognitive test scores and downgrading the severity (M=69, SD=14.3) or not (M=68, SD=13.4) within the diagnostic turn ( $t(63)=-0.287$ ,  $p=0.775$ ) (details in Appendix D 1). This minimisation of the patient’s dementia severity therefore appears to have a use other than explaining the patient’s symptoms. Characterising the patient’s dementia as “mild” and thus different from images they may hold of late stage dementia and the lack of independence that may bring works to soften the blow of the diagnosis. Additionally, this can work against resistance: the emphasis on the mild form of the patient’s condition may provide a reason why the patient has the dementia but not be acting how they may consider someone with dementia to act.

## 3. Re-referencing the evidence

### **(13) [P50\_H43]**

1 DR: now **all that informa:tion**, (0.5) the **the questions and**

2           **the sca:n**, (0.3) with **what you have to:ld us**  
3 CR: yeah  
4 DR: **bo:th to my colleagues**,  
5 PT: yeah  
6 DR: it seems (.) you are developing: (0.3) Alzheimer's  
7           disease.=>which is a< type of (.) dementia.  
8           (.)

Within the diagnostic turn the doctor in extract 13 references “all that information”, which he specifies as being from “the questions”, indicating the test results, “the scan”, and “what you have told us both to my colleagues” (lines 1-4). As discussed previously, doctors will reference the evidence in diagnosis delivery when they need to demonstrate their accountability for the diagnosis (Peräkylä, 2005). This also occurs in primary care when there is a temporal gap between the examination and the diagnosis, which there always will be in the memory clinic structure (even when the tests and diagnosis happen on same day), and when there may be some resistance on the part of the patient, which is also common in dementia. Referencing the evidence in diagnosis deliveries also increases the likelihood of patients engaging in diagnosis discussions (Peräkylä, 2005). Therefore, by re-referencing the previously discussed evidence from the testing in the diagnosis itself, doctors could be encouraging patients to respond, and thus eliciting their understanding or acceptance of the diagnosis.

#### 4. Direct versus Inferential diagnosis delivery formats

The last feature of the design of the diagnosis turn was related to whether doctors delivered the diagnosis directly or through inference. At one end of the scale – a direct diagnosis delivery – the diagnostic label is introduced as what Maynard (Maynard, 2004, :53) calls “*an attribute of the person*”, i.e. something that the patient “has” or “is”.

#### **(14) [P23\_H21]**

1 DR: I think **you ha:ve** what we wou- ca:ll Alzheimer's  
2           disease?  
3           (1)

On the other end of the scale – an inferential diagnosis delivery – the diagnosis is named as a medical explanation for the symptoms displayed on the testing, an action Maynard terms “*labelling the evidence*” (Maynard, 2004, p64). The diagnosis is not attached to the patient, but an inference or syllogism has to be made that if the patient has done tests that show X, and X constitutes a diagnosis, then the patient has the diagnosis.

**(15) [P104\_H40]**

1 DR: .tch so I think u:m, (0.4) wha:t u::m (0.4) if- **the most**  
2 **common cau:se** for that kind of pictu:re (0.4) and this  
3 kind of (.) picture on the (.) on the memory tests (.)  
4 is a: **is a problem** called Alzheimer’s disea:se  
5 (0.4)

As discussed in the introduction, previous CA work has shown that syllogistic diagnostic formats requiring inference from the results of diagnostic tests are particularly utilised when patients are showing resistance (Maynard, 2003a, Monzoni et al., 2011b). Given the fact, as demonstrated in Chapter 4, patients in memory clinics often display resistance to the formulation of their symptoms as severe enough to be a dementia, a diagnosis delivered through inference may be advantageous for doctors in order to avoid disagreement. Additionally, these diagnosis deliveries that require patient inference allow the patients to come to the realisation that they have the diagnosis themselves, and are less abrupt than direct diagnoses. However, people with dementia may have impaired reasoning skills and difficulties with abstract thinking, and thus a diagnosis based on inference might be more difficult to understand than for patients without cognitive impairment. Therefore, doctors in memory clinics have a dilemma in delivering the diagnosis in a format that is sensitive to likely disagreement and negative impact versus a format that will ensure understanding in the face of possible cognitive impairment.

In examining the directness of dementia diagnoses, there were 4 different diagnostic formats identified. These formats differ in the inferential leaps required for the patient to recognise that they have dementia.

#### 4.1 No Inference Needed

In these diagnosis deliveries the dementia label is explicitly presented as an attribution of the patient, and thus the patient does not need to make an inference between the naming of dementia and dementia being their diagnosis.

The most common configuration of these deliveries consist of the doctor stating the patient “has” or “has got” dementia (line 1).

#### (16) [P31\_H21]

```
1 DR: oka:y (.) so we think that you have a <dementia:,>  
2 (0.6)
```

To say someone “has” a condition is demonstrating that it belongs to them, and thus the diagnosis and the patient are immediately connected. Maynard describes these formats occurring in developmental disabilities clinics, with doctors also stating that the patient “is” a condition (“he is retarded”) (Maynard, 2004). There are no cases in the memory clinic data where the doctor says the patient “is” their diagnosis. However, in a minority of cases the doctor names the diagnosis as something that the patient is experiencing.

#### (17) [P183\_H49]

```
1 DR: .hhh (0.4) putting that all together, (.) I think that  
2 (0.9) although it's only a clinical diagnosis, .h there  
3 probably is a suggestion (.) that you are in: the very  
4 early stages of an Alzheimer's dementia.  
5 (0.5)
```

The preposition “in” (line 3) describes something as enclosed or surrounded by something else. To say someone “is in” something is again to directly connect the person with that thing. Therefore, there is also no inference required for the patient to see that they are receiving a diagnosis.

#### 4.2 Inference from own problem to diagnostic cause

This format requires a small amount of inference. In these formats the doctor attributes a “problem” to the patient, and in the same turn names the diagnosis as the cause of this problem.

##### (18) [P89\_H24]

```
1 DR: u:m so I think probably:, the cause of your memory  
2 problems is what we call a Parkinson’s disease dementia.  
3 (0.5)
```

The diagnosis is delivered as “the cause” of the symptom that is directly attributed to the patient: “*your* memory problems” (line 1). This describes an explicit relationship between the diagnostic label and the patient’s problem. The patient’s problem is presented as something that belongs to them, and this is immediately connected to the diagnosis, which means that there is only a minimal inferential leap to be made by the patient to understand they have a diagnosis of dementia.

This format can vary slightly in naming the patient’s “diagnosis” rather than their “problem” (line 3).

##### (19) [P16\_H02]

```
1 DR: sh m from my assessment (.) last year: (.) and from  
2 (0.6) uh:: what (CN name) suggested (.) every uh: (0.6)  
3 how things have evolved ever since (0.4) your diagnosis  
4 is (0.9) one of what we call (0.4) a (0.3) mild (0.6)  
5 dementia type of illness.  
6 (1.2)
```

The diagnosis is something that the patient owns (“your diagnosis” line 3), and then this diagnosis (rather than the patient) is labelled as “one of what we call a mild dementia”. It may be that in labelling the “diagnosis” rather than the “memory problems” the doctor presents an easier inference for the patient to make, as this does not require an acceptance of the memory problems in order to process the diagnosis being delivered. However, it is the “diagnosis” rather

than the patient themselves that is attributed the label of dementia, and thus there is some inference required.

#### 4.3 Inference from diagnosis definition to own situation

In these formats the doctor gives a generic definition of dementia and attributes this to the patient's test results or living situation. What is noticeable in these formats is the increased use of indexical terms (e.g. "that", "it") in the place of attributions or diagnostic labels.

#### (20) [P42\_H50]

1 DR: .pt .hhh and (.) in order to have >a diagnosis of  
2 dementia< you see: it's not just memory problems, (.)  
3 .hh it's memory problems (0.6) plus other problems .hh  
4 that have .h (.) got to have an effect on how you live  
5 your life  
6 CN: m[m. ]  
7 DR: [>so you] don't< live (.) it as well as you used to.  
8 CN: yeah.  
9 (0.3)  
10 DR: .hhh >and I-< and I think **that's probably what's going**  
11 **on in your ca:[se.=.hh]** I- I think i- **it would all fit**  
12 PT: [mm: m ]  
13 DR: with a dementia wha[t's **wha]t's happe[ning to] you.**  
14 CN: [mm ]  
15 PT: [mm: ]

The doctor begins the diagnosis with an overview of how one comes to "have a diagnosis of dementia" (lines 1-9). The use of the phrase "in order to have.." and "it" (line 2) places this description into a generalised story-telling format, and therefore while "you" is used twice (lines 4 and 7), these are generic and do not reference the patient. There has been no discussion of the patient's day-to-day life at a prior point in the meeting that this symptom description of "you don't live it (life) as well as you used to" (line 7) could be referring to. However, this could have been discussed in the assessment stage, and thus the doctor's pause at this point is potentially aimed at eliciting acknowledgement. He gets this verbally from the patient's wife, and the patient produces a tiny nod.

The doctor then attributes the symptoms to the patient (lines 10-11). The “that” (line 9) indexes the prior description (lines 1-6), which the doctor presents as happening to the patient – “going on in your case”. While this could be seen as the initial diagnosis delivery with a syllogistic format, the doctor rushes through re-stating the diagnostic label (lines 10 and 13). Again there is the indexical “it”, which “fits with dementia”. However, this is not explicitly linked to the patient until the end of the doctor’s turn (line 13), where the “it” is seen to refer to “what’s happening to you”. Therefore, by the completion of the doctor’s turn the patient’s experience is tied to dementia and thus the diagnosis is delivered.

This format of delivery commonly occurs in multi-unit turns, which, as described in Chapter 2, may lead to misunderstandings in people with cognitive impairment. The deliveries that use this format also require multiple levels of inference. Firstly, it may be expected that if the doctor is providing a generalised description of what a dementia diagnosis is, the patient will start to infer that this description applies to him. The doctor specifies the description and attributes it to the patient’s own experience – but in doing so uses the indexical “that”, requiring the patient to make the inference that the “that” refers back to his symptoms. Furthermore, when it comes to the diagnosis, dementia is named as something that “it would all” fit with, requiring the patient again to make the inference that the “it” refers to his symptoms. The doctor’s addition of “what’s happening to you” at the end of the turn perhaps seeks to rectify this, but again is indexical and does not specify “what” is happening. Therefore, the patient will need to make multiple inferences that this diagnostic label is connected to his memory difficulties in order to come to the conclusion that he has a diagnosis of dementia.

#### *4.4 Fully inferential diagnosis deliveries*

Deliveries using this format contain no attribution of a diagnostic label or symptom to the patient. The patient’s symptoms are established in the earlier stages of the meeting (through test feedback and elicitation of perspective on symptoms), and while the test results are usually referred to in the delivery, this is done in an abstract manner with no attribution to the patient. While the diagnosis is always named, which is not always the case in other settings



(Maynard, 2004, Monzoni et al., 2011a), it is done through the use of indexical terms linking back to a generic symptom description.

**(21) [P138\_H40]**

1 DR: it's hh (.) they- we we ca:ll this combination of  
2 (.) you know: m memory difficulty and blood vessel  
3 change in the brai:n  
4 PT: mm:  
5 DR: **we call that vascular dementia.**  
6 (.)

The doctor states the patient's symptoms but does not attribute them to the patient, using "this" instead of "your" that is used in the first two formats (lines 1-2). He then delivers the diagnosis (line 5), linking the diagnostic label back to the generalised symptom description with "we call that..". He is therefore labelling the evidence, not the patient, with the diagnosis, similar to the previous format. However, in these cases the fact that the evidence is also not attributed to the patient means that an additional inference has to be made.

When these formats of delivery are used the patient has to make a full inferential jump back to the test feedback stage of the meeting. The generic reference to the patient's symptoms, with the indexical "this", requires the patient to remember that her test results showed those particular symptoms. The naming of the illness then refers back to the evidence with the "that", thus labelling the evidence with the dementia diagnosis rather than the patient or the patient's symptoms, requiring further inference. Therefore, at no point in these deliveries is the diagnosis or the symptom attached to the patient.

There are thus 4 diagnostic formats used in memory clinics, varying in the amount of inferential reasoning the patient needs to make from the diagnosis being named to them having the diagnosis. Patients will either need to make no inference when the diagnosis is delivered directly, make an inference that their problem is caused by dementia, make multiple inferences that their symptoms are the same as that which is caused by dementia, or make the inferential leap from the definition of dementia as a certain set of symptoms to those symptoms discussed in the testing as fed back earlier in the meeting.

Frequency of diagnosis delivery features

<b>Diagnosis Feature</b>	<b>Frequency</b>
Introducing dementia as a medical label	40 (49%)
Minimising the diagnosis severity	34 (42%)
Re-referencing the evidence	45 (55%)
Delivery format	
No inference	33 (41%)
Inference from own problem to diagnostic cause	8 (10%)
Inference from own problem to diagnostic definition	9 (11%)
Fully inferential diagnosis	31 (38%)

**Table 8: Frequencies of diagnosis features**

While the first three features of the diagnostic turn occur independently in approximately half of the meetings, the vast majority (n=76, 94%) contain at least one of these features. In memory clinics there are more cases where the diagnosis requires some level of inference than those that require none (see Table 8). However, in 41% of cases the doctors deliver the diagnosis directly to the patient, ensuring that there is no need for inference.

Quantitative analysis demonstrates that there is a relationship between cognitive test scores (only ACE-III scores used because they were in the majority n=65) and the diagnostic format requiring no inference (M=63.72, SD=13.3) versus those requiring some level of inference (M=70.78, SD=13.3) ( $t(63)=2.07$ ,  $p=0.042$ ) (Appendix D 2). In other words, doctors are using direct diagnostic formats more often when patients are more cognitively impaired.

Summary

Doctors are using different diagnostic formats requiring different levels of inference for patients to understand that they have a diagnosis of dementia. Diagnosis deliveries requiring inference are the most common formats used, similar to other settings with contentious diagnosis deliveries. However, direct diagnosis deliveries that require no inference from the patient's symptoms to their diagnosis make up 41% of the diagnoses. Quantitative analysis shows

doctors use diagnosis deliveries requiring no inference more commonly with patients with more cognitive impairment.

## **Discussion**

Dementia diagnosis delivery sequences reflect the delicate balance involved in delivering a dementia diagnosis: minimising likely resistance and distress, while simultaneously maximising understanding given likely cognitive impairment.

The majority of deliveries begin with doctor turns indicating that there is a diagnosis, but without using the diagnostic label. The turns in these locations are primarily utilised by doctors to ensure patients are oriented to the diagnosis phase of the meeting. Additionally, these turns can also be used to characterise dementia in a particular way, and thus downplay the diagnosis prior to delivery.

Doctors also characterise dementia when delivering the diagnosis by introducing the diagnosis as a medical term and emphasising the early or mild stages of the patient's illness. Additionally, evidence is often re-referenced in the delivery. In the majority of diagnosis deliveries doctors avoid attributing the illness directly to the patient ("this is dementia"), thus requiring the patients to infer that they have received a diagnosis from the information presented, which is a method to avoid both disagreement and strong negative responses.

However, 41% of dementia diagnoses are delivered in a direct format ("you have dementia"), requiring no inference from the patient and thus enhancing the likelihood of understanding the diagnosis.

Before discussing the effect of these strategies on managing this balance between ensuring understanding and avoiding resistance and distress, it is important to discuss how much of what has been observed in memory clinics is specific to the setting. It is certainly the case that many of the behaviours observed in dementia diagnosis delivery have also been shown to occur both in bad news interactions more generally and in other diagnosis settings. There is evidence throughout the dementia diagnosis sequence of hesitancy, in-breaths, pauses, and re-starts, which are common in all bad news deliveries (Maynard, 2003b). The use of pre-diagnosis practices has not been systematically documented in other settings: so while they may be aimed at the re-orientation

of patients with likely short-term memory and concentration deficits, there may also be wider functions linked with deliveries of diagnostic news more generally. For example, the build up to the diagnostic news through pre-diagnosis is also demonstration of the shrouding and delay of bad news evident in many diagnosis deliveries (Maynard, 2003b, Turowetz and Maynard, 2016). Additionally, pre-diagnoses not only orient patients to the diagnosis being the next action, but also strongly forecast the nature of the news, a device that also occurs in other medical settings (Maynard, 2003a, Stivers, 1998). Further research is needed to see whether the particular pre-diagnosis practices described are used in other diagnostic settings in order to see whether these are specific to dementia diagnosis or are characteristic of diagnostic interactions more generally.

Pre-diagnoses may also be a result of 'breaking bad news' training that doctors receive in medical school. The majority of doctors are not trained to deliver diagnoses of particular conditions, but receive training on delivering bad news more generally, which will include feedback of unsuccessful treatment or reporting deaths to families. Additionally, while some breaking bad news guidelines are more common than others (Kaplan, 2010, Silverman et al., 1998), the doctors are unlikely to have all received all the same training. However, many breaking bad news guidelines include similar features to those in the memory clinic data. For example, the SPIKES protocol for delivering bad news advises doctors to give a "warning" to patients (e.g. *"I've got bad news I'm afraid"*) with the idea that this will lessen the shock when the diagnosis is delivered (Kaplan, 2010). The pre-diagnosis practice where doctors state a problem with a cause may be an example of doctors providing this warning, although is not as explicit as that which is recommended in the guidance. Additionally, an elicitation of how much information the patient wants to know regarding their diagnosis is advised in many breaking bad news guidelines, as well as the NICE and the MSNAP national guidelines for dementia (National Institute for Clinical Excellence, 2006, Hodge et al., 2014). However, it should be noted that this part of the diagnosis guidelines is usually taken to mean that consent to name the diagnosis should be discussed prior to, rather than within, the diagnosis feedback meeting (Guss, 2014).

However, the analysis suggests that while the pre-diagnosis practices could be a result of generalised guidance provided to clinicians, or particular interactional features of delivering bad news, how they are applied appear to be specific to the dementia context. People with dementia often have memory difficulties and/or difficulties in attention and concentration, particularly in the early stages of Alzheimer's disease, which makes up a large proportion of the sample. These symptoms may result in difficulties following lengthy discussions containing detailed information. Despite the diagnosis phase usually following strong forecasting in the test feedback stage, patients may have lost concentration or forgotten the information discussed at any point during the interaction. The fact that three pre-diagnosis practices explicitly marking the diagnosis as the next action were identified and used in the vast majority of the meetings illustrates doctors placing great importance on patient orientation to the diagnosis feedback right up to the moment where they deliver the diagnosis. Additionally, it was evident from the data that if patients did not provide a go-ahead to the pre-diagnosis – i.e. blocked the move to diagnosis delivery – doctors would halt the progression to the diagnosis and pursue a response until a go-ahead was obtained from the patient. The pre-diagnosis sequence therefore appears to be particularly important to ensure patient readiness for delivery before stating the diagnosis.

Another feature of the pre-diagnosis, which is also evident in the design of the diagnostic turn itself, is doctor management of potential patient resistance. While patient resistance to diagnosis is in no way specific to dementia, there are numerous reasons why patients may resist a dementia diagnosis. Throughout the data there were examples where patient responses to pre-diagnosis were indicative of resistance to the projected diagnosis (e.g. extract 10, page 137). When this occurred, doctors again halted the progression to the delivery turn and implemented another pre-diagnosis practice, sometimes repeatedly, until eliciting an adequate signal from the patient to continue. The fact that these signals could be extremely minimal (often just nods or minimal continuers such as “mm” or “yes”), demonstrates doctor authority in progressing the meeting – with passivity from the patient being the preferred option (Robinson, 2003a). The management of this resistance continues into the delivery turn, with doctors presenting the dementia diagnosis explicitly as a

medical term through the use of phrases such as “a condition called..”. This placement of the diagnosis in the clinician’s epistemic domain presents it as something different from the patient’s preconceptions of dementia, and thus is attentive to potential resistance.

Doctors also re-state the evidence for the diagnosis – the scan, test results, or patient symptom history – within the diagnosis sequence. Both Peräkylä and Maynard have demonstrated the utility of presenting the evidence within the diagnosis phase of the meeting to indirectly contradict any patient opposing views of the diagnosis (Maynard, 2003a, Peräkylä, 2005). Re-stating the evidence emphasises the doctor’s diagnostic reasoning and thus shows accountability for the diagnosis, but is also again a display of epistemic authority and therefore minimises opportunities for patient resistance. In Peräkylä’s primary care data, while evidence was indexed or placed adjacent to diagnosis in the majority of cases, doctors were shown to explicate the evidence in 39% of deliveries. Explicating the evidence is much more common in memory clinics, occurring in 80% of meetings either within the pre-diagnosis sequence or the diagnostic turn. Additionally, Peräkylä found a statistical link between the contentiousness of the diagnosis and whether doctors referenced the evidence in delivery. Given the fact that dementia is very likely to be a contentious diagnosis regardless of whether patients believe they have symptoms or not (due to the stigma and equation of symptoms to normal ageing, as discussed previously), the fact that evidence is re-stated so often in memory clinic diagnosis sequences supports Peräkylä’s findings.

Another factor in delivering a dementia diagnosis is the negative impact of the diagnosis. Studies of patient initial responses to diagnosis show that shock and distress can be common (Aminzadeh et al., 2007, Carpenter et al., 2008). Therefore, it is perhaps unsurprising that there is evidence within the pre-diagnosis and in the design of the diagnosis turn that doctors aim to minimise the negative effect of the diagnostic news. Characterising dementia in the pre-diagnosis sequence appears to work in a number of ways in managing the patient’s responses. Doctors were observed to emphasise uncertainty in coming to their diagnostic conclusions, and also topicalise medication and support available to people with dementia diagnoses. This was also noticeable

within the diagnostic turn itself, with many doctors emphasising the patient's dementia as being "mild" or "early". The fact that the use of these terms does not appear to be associated with the severity of cognitive impairment on the testing suggests that doctors implement this strategy particularly to manage the negative effect of the diagnosis on the patient. Patients and their families report that while they want diagnostic information communicated clearly, they also want to be able to maintain hope after receiving a dementia diagnosis, and thus strategies such as this may mean they can maintain that hope (Mastwyk et al., 2014). However, patients and their families report that the uncertainty is one of the primary challenges surrounding assessment and diagnosis (Campbell et al., 2016), and it may be that too much emphasis on continued uncertainty will have a negative effect in itself.

Doctors thus appear to be managing the patient's orientation, potential resistance, and negative responses within the design of the pre-diagnosis and diagnosis turns. The fact that doctors deliver diagnoses using different levels of attribution of dementia to the patient, requiring different levels of inference for the patient to understand they are receiving a diagnosis of dementia, relates to all of these factors. The utility of inferential diagnostic formats (where the diagnosis is not attributed to the patient – "this is dementia" rather than "you have dementia") has been demonstrated repeatedly in settings where resistance to diagnosis is common (Maynard, 2004, Monzoni et al., 2011b). Additionally, delivering diagnoses as upshots of evidence from the testing – thus requiring patients to make the inference that they have the diagnosis – is a method to minimise the strong negative responses within the clinic (Maynard, 2003a, Yoon et al., 2015). In Monzoni and Reuber's data on non-epileptic seizures diagnosis discussions, they state that "overt attributions..were a minority", and that "rare were the cases" that neurologists used explicit diagnostic labels (Monzoni and Reuber, 2015). Gill and Maynard describe "asserting the condition" with evidence from testing being demonstrated as being "more common" than not including evidence (Gill and Maynard, 1995). Additionally, Maynard described these formats as being common in oncology and HIV settings (Maynard, 2003a). Therefore, it is not surprising that these formats are used in the majority of the memory clinic diagnosis deliveries.

However, in oncology, HIV, neurology, or with parents of children with developmental disabilities, it is likely that people will be able to make the inferential leap required from the statement of the evidence to understanding a diagnosis has been delivered. There is evidence that some people with dementia have difficulty holding representations of information necessary to always successfully make these connections (Weirather, 2010, Almor et al., 1999). This will be made even more difficult by the fact these types of diagnoses are often delivered over multi-unit turns, which may be difficult to follow with cognitive impairment (Elseley et al., 2015). This may be one of the primary reasons that a large proportion, over 40%, of diagnoses delivered in memory clinic are direct attributions of diagnosis to the patient, thus requiring no inference for the patient to realise they have dementia. A further 27% of the diagnosis deliveries contained some level of attribution of the illness to the patient – either through placement of the diagnosis as the name of the patient’s problem or diagnosis, or through linking the diagnosis to the patient’s situation. These formats require less inference by the patients to understand that they are receiving a diagnosis than straight indirect formats, and thus may also be a method to maximise understanding. This is supported by the fact that doctors were more likely to use direct diagnosis formats when patients have lower cognitive test scores supports the use of these formats to enhance patient understanding. It would be interesting to compare the frequencies of direct and inferential diagnosis formats with other settings to see if direct deliveries are more common in memory clinics, which would further add to the theory that doctors are using these formats to compensate for possible cognitive impairment and ensure understanding.

When considering the use of direct deliveries versus deliveries requiring patient inference, the dilemma faced by clinicians delivering dementia diagnoses is thus evident. Patients may resist the doctors’ formulation of a diagnosis of dementia for any number of reasons. Therefore, using indirect diagnosis formats, showing the logical progression from the evidence to the diagnosis without directly labelling the patient, is an important strategy to encourage acceptance. Additionally, patients are likely to find the fact they have dementia distressing. Therefore, the use of indirect diagnosis formats, avoiding abrupt delivery of the bad news, will lessen the shock of receiving a diagnosis.



However, people with dementia will also have problems processing and understanding complex information. Therefore, direct delivery formats, minimising the inference needed for patients to understand they have a diagnosis, will enhance understanding. Doctors therefore have to choose between the delicate, indirect approach that should avoid resistance and negative emotional responses, and more abrupt, direct deliveries that maximise patient understanding of their diagnosis. Given that there has been an emphasis in increasing early diagnoses of dementia to encourage decision making, it might be that maximising patient understanding is expected to be given greater emphasis.

This chapter illustrates how doctors deliver dementia diagnoses. Strategies have been identified that, while also being features of bad news delivery in general, appear to have particular functions in dementia diagnosis delivery. We have not yet discussed in detail the effect of how doctors approach and deliver the diagnosis on patient responses and the progression of the diagnostic feedback meeting. As Byrne and Long (1976) demonstrate, both doctors and patients are oriented to diagnosis deliveries as projecting treatment recommendations. Therefore, how the interaction unfolds after diagnosis, i.e. how the patient responds and how doctors deal with these responses, are of particular interest when it comes to examining dementia diagnosis delivery.

**Chapter Six:**  
**“Have you heard of the word  
dementia before?”**  
**Responses and Pursuits of  
Responses to Dementia Diagnosis**

This chapter will present the response to the diagnosis in three sections: the initial response, doctor pursuit of response, and the patient's later response.

## Patient Initial Responses to Diagnosis

### Minimal Initial Responses to Diagnosis

The majority of patients initially responded minimally to the dementia diagnosis.

#### (1) [P83\_H23]

1 DR: but I think (0.4) u::m, (.) .tch .hh my my se:nse (0.4)  
2 i:s, (0.6) putting all this together I I think the most  
3 likely explanation fo:r your memory problems (.) is  
4 probably early Alzheimer's disea::se.  
5 PT: °mm.°

The patient utters a quiet, low-intonation “mm” after the diagnosis delivery. He has little non-verbal response, looking down just after uttering “mm” but with no other movement. Diagnosis delivery sequences are routinely accomplished in this manner, with the doctor providing the diagnostic label and minimal patient acknowledgement being the typical next action (Heath, 1992, Peräkylä, 2005). By contrast, treatment recommendation discussions normatively require agreement from patients for the doctor to progress to the next stage of the meeting, and therefore minimal tokens can be heard as withholding a response where one is required, indicating resistance (Stivers, 2005). However, minimal acknowledgement tokens in diagnosis sequences are generally treated as unproblematic, regardless of the severity of the diagnosis involved (Heath, 1992, Peräkylä, 2005, Maynard, 2003b).

There is nevertheless a range among the minimal patient responses. The patient's response in extract 1 is a typical minimal response: “mm” with non-changing intonation. These tokens are unmarked and thus hearably indistinguishable from back channels or continuers, but signal reception via their placement after a completion of an information-providing turn. By contrast, some minimal responses are marked, in pitch or intonation.

### (2) [P150\_H41]

1 DR: okay. .hhh well what we think is going on here is that  
2 you've got (.) u:m Alzheimer's disea:se,  
3 (0.3)  
4 PT: m: :m.

### (3) [P185\_H44]

1 DR: from what the test is showing te- was saying .hh a:nd  
2 wha: the: scan was saying is that it is a part of .hh a  
3 dementia;  
4 (1.2)  
5 PT: m: hm;

The emphasis on the “mm” in extract 2 and “mhm” in extract 3 both indicate more active participation than the unmarked “mm” in extract 1 above (Nenova et al., 2001). The lengthening and downward intonation of the “mm” in extract 2 can be a sign of recognition and “*thought-worthiness*” (Ward, 2006, :13). Additionally, these emphasised, downward intoned responses are “backwards looking”, with patients actively passing up the opportunity to speak and shape the following interaction (Heath, 1992). In contrast, the rising intonation “mhm” on the patient’s response in extract 3 is hearable as a continuer and thus potentially a request for more information (Ward, 2006). An exploration of how the doctors follow these initial responses will be the topic of the next chapter.

Patients can also respond with “yes” or “yeah”.

### (4) [P177\_H44]

1 DR: .hh it's looking like an ear:ly form of a dementia:.  
2 PT: **yeah**.

Heath (1992) and Peräkylä (2005) both class “yeah” as the same as “mm” or “mhm” – a minimal acknowledgement of the diagnosis. Gardner (1997) however argues that “yeah” shows stronger alignment with the previous statement than “mm”. Jefferson (2009) demonstrated that “yeah” indicates a desire to “shift from reciprocity to speakership”, and thus displays a wish to play an active role in the interaction. However, she also illustrated that some people use “yeah”

both as a neutral continuer and to shift to speaking, and thus it may have numerous functions.

Many patients do not respond verbally, but just nod or make another non-verbal acknowledgement gesture, such as shifting in the chair or moving closer to the doctor. There are also some patients who do not respond verbally or non-verbally. While silence may be a request for elaboration (Maynard, 1997) and thus not necessarily indicate lack of engagement, there has been little research on its role in diagnosis delivery sequences (Peräkylä, 2005). An exploration of the link between patient initial response and later response to the diagnosis will be addressed later in this chapter.

### Extended Responses to Diagnosis

Peräkylä defines extended responses to diagnosis as when patients “*do something more than minimally acknowledge the diagnosis*” (Peräkylä, 2005, p234). He categorises the types of patient responses as ‘displaying agreement’ or ‘resisting the doctor’s diagnosis’. In the latter case of resistance, Ijäs-Kallio et al (2011) describe patients replacing conventional acknowledgement markers such as those described above with a misaligned action such as describing a contrary symptom or different doctor report. There are no overtly resistant initial responses in the memory clinic data. Instead, even the non-minimal, i.e., extended responses tended to be minimal in content.

#### **(5) [P186\_H68]**

1 DR: .hh we do think you have (0.4) uh:: what we ca:ll, (0.9)  
2 m- memory difficulties which are more than your age=what  
3 we call dementia:.  
4 PT: ↑oh: **really**.  
5 DR: mm::

Responses such as “oh really” (line 4) are news receipts, in that they indicate that the diagnosis is news for the patient. However, oh-prefaced news receipts, while sometimes requiring a confirmation in the next turn (which the doctor provides, line 5), often mark the end of news announcement sequences and thus generally discourage further elaboration of news (Maynard, 2003a).

Patients' oh-prefaced news receipts sometimes include a negative assessment, and therefore an explicit demonstration from the patient that the news is bad.

#### (6) [P145\_H49]

1 DR: .hh and I think- (.) you are in the early stages (0.4) of  
2 a dementia;  
3 (0.3)  
4 PT: oh dear.

The emphasised “oh” of the patient’s response indicates the newsworthiness of the diagnosis, and the “dear” provides a negative assessment. In bad news deliveries in general conversation, recipients rarely offer negative assessments when the news affects them directly, because it illustrates self-pity, which is dispreferred in interaction (Pomerantz, 1978). This also holds in clinic settings, where stoic responses are the norm (Maynard, 2003b). This may explain why, when these negative initial assessments do occur, they are often in a minimal news receipt format and thus discourage elaboration from the doctor.

While negative initial responses to the news are not common, they do also occur in more expansive formats, illustrating negative perceptions of the consequences of dementia.

#### (7) [P19\_H07]

1 DR: um (1.5) it- it looks very much (0.5) like you've got  
2 Alzheimer's disease.  
3 (5.8)  
4 CN: w- what are the main variation[ns?]  
5 PT: [and] tha:t's progressive;  
6 DR: °mhm° yes it is (.) yes.

In this extract the doctor pauses for nearly 6 seconds waiting for the patient to respond (line 3). This length of pause, with the doctor keeping silent to encourage patient response, is a rare occurrence in diagnosis delivery sequences in other settings (Robinson, 2003a). The patient is looking at the doctor during the diagnosis, but her eyes drop down to the floor after the

delivery. The patient's son answers first, but the patient responds in overlap, looking back up to the doctor as she does so (lines 4-5). It is the patient's response that the doctor attends to, confirming the progressive nature of the illness (line 6). In requesting confirmation of the negative prognosis of dementia the patient acknowledges the diagnosis delivery and demonstrates her negative understanding of dementia: that it is a condition that gets worse. Furthermore, she encourages the doctor to elaborate on the diagnosis discussion, requesting further information.

Patients can also respond to diagnoses with clarifications or requests for more information which are non-valenced, i.e. they do not contain assessments.

### **(8) [P31\_H21]**

1 DR: oka:y (.) so we think that you have a <deme:ntia:,>  
2 (0.6)  
3 PT: ↑**what does that mea::n.**  
4 DR: °that's what I was about to say.°=it means basically  
5 just what I sai:d; that, .hhh (0.4) because your brai:n  
6 has shrunk a little bit, (0.4) it's (0.4) u:m, (0.4)  
7 making you: it's making you remember <things less  
8 well,>

The patient's question in line 3 acknowledges the news and encourages elaboration, but demonstrates a lack of knowledge of dementia (line 3). The doctor responds with a definition of dementia, prefaced with a claim that this is what she was intending to do regardless of the patient's request, and marking this as a repeat of prior talk (lines 4-7).

### *Initial Responses to Diagnosis: Quantitative analysis*

Patients most often responded to the dementia diagnosis non-verbally or with a minimal, non-marked, acknowledgement token (frequencies in Table 9). Not responding to the diagnosis was not uncommon, with 13% of patients not responding verbally or non-verbally. Nearly a quarter of patients responded with either "yeah" or "mm" marked with a questioning or emphasised intonation.

Patient Response to Diagnosis		Frequencies
<b>None or Minimal</b> n=59, 73%	No response	10 (13%)
	Non-verbal	20 (25%)
	Minimal acknowledgement	11 (13%)
	“Yeah”	9 (11%)
	Marked “mm”	9 (11%)
<b>Extended</b> n=22, 27%	News receipt or change of state token	11 (13%)
	Clarification question	3 (4%)
	Negative assessment	8 (10%)

**Table 9: Frequencies of initial responses to dementia diagnosis**

Similar proportions of the patients responded not at all or non-verbally (38%) and with a minimal response (35%), with 73% of patients not responding with more than a minimal acknowledgement token to the dementia diagnosis. These proportions are similar, slightly larger, to the 67% minimal responses reported in primary care (Peräkylä, 2005).

Over a quarter of patients initially responded to the diagnosis with something more than a minimal response. Half of these responded with a change of state token (“oh”) or a news receipt (“really”), thus demonstrating that the diagnosis is news to them. Fourteen per cent of patients responded more extensively, with negative assessments of the news (10%) or questions (4%).

There was no association between type of dementia and initial response to the diagnosis (Appendix E 1). Patients were more likely to initially respond extensively to the diagnosis when doctors delivered the diagnosis directly (“you have dementia”), compared to when it was delivered through inference (“this is dementia”) ( $\chi^2(1, N=81)=4.213, p=0.040$ ) (see Table 10, more details in Appendix E 2).

**Table 10: Delivery format and type of response**

	Minimal Response	Extended Response
<b>Delivered through inference</b>	39	9
<b>Not delivered through inference (direct delivery)</b>	20	13



Patients who initially responded minimally to the diagnosis had higher scores on the ACE cognitive test ( $M=71.42$ ,  $SD=12.58$ ), so were less cognitively impaired, compared to people who initially responded extensively to the diagnosis ( $M=60.50$ ,  $SD=13.25$ ) ( $t(63)=3.182$ ,  $p=0.002$ ) (Appendix E 3).

### Summary

Patients did not initially demonstrate explicit resistance or explicit, extended agreement with the doctor's diagnosis in memory clinics. The majority of patients responded minimally, non-verbally or not at all to the dementia diagnosis, thus conforming to the normative diagnosis delivery and response sequence format. However, there was variation in the minimal responses, with some responses marked with changing intonation and emphasis. When patients do produce extended responses they can discourage or encourage elaboration. Negative initial responses to diagnosis are rare. Extended initial responses to the diagnosis are more likely when doctors directly attribute the diagnosis to the patient in the delivery, and when patients are more cognitively impaired.

### **Doctor pursuit of patient responses**

As discussed in the introduction, previous CA studies of diagnosis delivery show that minimal response is oriented to as sufficient by doctors and patients, with doctors typically moving discussions on from diagnosis straight to treatment (Stivers, 2005, Robinson, 2003a, Maynard, 2003a). In fact, when doctors halt this progression to treatment in primary care, patients will ask about treatment in order to re-initiate the normal transition of activities (Robinson, 2003a). However, in nearly all of the dementia diagnosis feedback meetings doctors do not move straight on to treatment, but instead appear to pursue patient responses beyond the initial response to the diagnosis. This occurs after both minimal and non-minimal initial responses.

As demonstrated in analysis of pursuits in general conversation, speakers pursue responses not only when no response has been given, but also when

the response supplied is deemed by the speaker as insufficient (Jefferson, 1981, Bolden et al., 2012). Stivers' study of treatment recommendations demonstrated that if patients either do not respond to treatment proposals or provide an insufficient response (such as resistance), doctors will expand and modify the recommendation in order to gain the desired response from the patient (Stivers, 2005). It could therefore be that doctors in memory clinics are using similar strategies for the diagnosis itself. As demonstrated above, extended initial responses to dementia diagnosis are either news receipts, negative reactions or clarification questions. Hence, doctors may be aiming for a different sort of response from patients before progressing to treatment discussions. The methods that speakers use to pursue responses can provide an indication of what it is in the initial response that is either missing or inadequate (Pomerantz, 1985). This will be explored in the following description of practices doctors use to pursue responses in memory clinics, as well an examination of the few cases where doctors do not pursue a response.

#### *Elaboration of diagnostic information as pursuit of response*

A common method to pursue a response is to add further information that makes a response relevant without explicitly orienting to a problem with the previous response through direct questioning (Bolden et al., 2012). This is evident in the dementia diagnosis deliveries, where doctors will elaborate on the diagnosis by adding additional diagnostic information. Similarly to how Peräkylä describes psychoanalysts pursuing client response to interpretations (Peräkylä, 2011), doctors add further elements to the diagnosis and thus provide further opportunities for patients to respond.

#### **(9) [P52\_H51]**

1 DR: >so it's< so it's (0.2) probably som:ething that we'd  
2 (.) we'd (.) call an Alzheimer disea:se.  
3 **(0.5)**  
4 DR: so so it is a: it is a re- it is a dementia type of  
5 illness:..  
6 (1)  
7 PT: °heh° (0.3) I hate all this word dementia.

The doctor delivers the diagnosis of Alzheimer's disease (line 1-2), and receives no verbal or non-verbal response (line 3) with the patient keeping his face very still, although he relaxes his mouth slightly in the pause (line 3). The doctor follows the patient's silence with a pursuit via recompletion of the turn, in essence re-delivering the diagnosis using another diagnostic term ('dementia', line 4). In doing this, the doctor is pursuing a particular response in that he *"provides material via which the recipient might construct a revised analysis of the utterance in question"* (Jefferson, 1981, p50): the patient may react to 'dementia' rather than 'Alzheimer's disease'. Furthermore, the use of a different diagnostic term shows that it is the diagnosis itself that requires a response. As "dementia" is uttered, the patient leans a little back in his chair, and starts moving his mouth. In the pause the patient is blinking and exhales silently, before responding with a quiet chuckle (line 6). He looks back and forth to his daughter and the doctor while providing a negative assessment of the diagnosis.

Elaboration of diagnostic information is similar to Maynard's descriptions of elaborations of all types of news, in that they *"offer the focal piece of the news, or provide details, such that a recipient can assess the news in a precise manner"* (Maynard, 2003a, :108). While these elaborations are not always designed as typical pursuits (i.e. there is no questioning intonation), the doctor's gaze towards that patient, and the long pause that follows, indicates an expectation that the patient responds (Stivers and Rossano, 2010).

There are numerous elements of information that doctors can use to elaborate on the dementia diagnosis. Many doctors provide further medical information or labels as in extract 9 above, often including the subtype of the dementia or describing the causes of dementia. Elaboration of diagnostic information by the doctor can however also appear to be specifically targeted at a potential reason for the patient's lack of response. These elaborations are similar to the *"remedial bids"* Gill describes doctors using to manage resistance to diagnosis from parents of children with developmental disabilities (Gill and Maynard, 1995, p20).

**(10) [P131\_H44]**

1 DR: based on that we would (0.7) think that it is more  
2 likely .hh to be: a mild Alzheimer's dementia:.  
3 (0.7)  
4 DR: .hh[h ]  
5 CN: [mm:]:.  
6 DR: but >whatever it is< it's early stages [>because it's<]  
7 PT: [↓ye(h):s ]  
8 DR: clearly (.) you're functioning very well and the test  
9 score: .h is on the: side where it is early [ or m]ild  
10 PT: [mm:. ]  
11 DR: [put it that] way.  
12 CN: [mm:: ]  
13 (.)  
14 PT: ↓yeah.  
15 DR: .HH so:, (.) that is (0.4) er that is what it is looking  
16 li:ke from the scan and from the [test and ] fro[m er ]  
17 PT: [↑oh ri:ght] [AKHH ]  
18 DR: .hh uh:  
19 (.)  
20 DR: so it it would mean that >like and because< it's early  
21 stages .h  
22 CN: m[m ]  
23 DR: [th]ere is a role for tablets medication to help slow  
24 down the illness.

The doctor is looking at the patient's wife when she finishes the diagnostic turn (line 2). After a pause the patient's wife responds minimally to the diagnosis (line 5), while the patient nods and shifts in his seat. The doctor turns to the patient and elaborates on the diagnosis by downgrading the severity of the patient's illness (lines 6-11). The patient responds with an emphatic and lengthened "yes" immediately after the doctor's downgrade (line 7), and nods and acknowledges the information with a downward-intoned, emphasised "yeah" at the end of the turn (line 14). However, the patient's eyes are closed in a prolonged blink when saying this. The doctor then re-explicates the evidence from the scan and the cognitive testing (lines 15-16), which had already been discussed prior to this extract. Re-referencing the evidence is a practice of accounting for the diagnosis and thus soliciting a response (Gill and Maynard,

1995, Peräkylä, 2005). The patient does respond to this in overlap with an emphasised news receipt – “oh right” – with an upward intonation on the “oh” indicating surprise. The patient then coughs, shifts in his seat, and looks away (lines 17-19). These non-verbal actions, alongside the news receipt discouraging further elaboration, are designed to curtail the diagnosis discussion. The doctor then progresses to the next stage of the medical agenda – the treatment and support discussions (lines 20-24).

Downplaying the severity of the dementia and re-referencing the evidence are two methods that doctors implement to encourage patient response. Another element doctors can add when elaborating on the diagnostic information is explicating the uncertainty of a dementia diagnosis in its early stages. Again, this is similar to the methods doctors use in developmental disabilities clinics – downplaying the certainty of the diagnosis in order to elicit agreement from patients (Gill and Maynard, 1995).

#### (11) [P183\_H49 (part 1)]

1 DR: .hhh (0.4) putting that all together:, (.) >I think  
 2 that< (0.9) >although it's only a< ↑clinical diagnosis,  
 3 .h there probably is a suggestio:n (.) that you a:re in:  
 4 the very ear:ly stages of an Alzheimer's dementia.  
 5 (0.5)  
 6 DR: tch .hhh now:, (0.3) I say probably:, (.) .hh becau:se  
 7 there's no hard and fast test (.) .hh that we can do  
 8 that gives us a definite answer .hh that somebody has  
 9 dementia or somebody doesn't,=.hhh and with you it is  
 10 quite tricky:, (.) .hh to make that diagnosis.  
 11 PT: >(ri:gh-/why:.)=why[:;]<  
 12 DR: [.h]hh because you're still  
 13 functioning at a very high level;  
 14 (.)  
 15 DR: tch .hhh ahh heh heh! .hh ffrom what your wife tells  
 16 u[s:ɛ]  
 17 CN: [heh] heh.  
 18 DR: tch [.hhh um:: ]  
 19 PT: [>g(h)osh did sh(h)e; <] ah ↑heh  
 20 DR: tch an:d although there are examples >I think< for

The doctor has already alluded to the difficulty in coming to the diagnosis within the delivery, saying that it is a “clinical diagnosis” and framing it as a “suggestion” (lines 1-4). The patient nods after the delivery turn is completed (line 5). The doctor elaborates, explicating uncertainty about a diagnosis of dementia, talking first in general terms that “there’s no hard and fast test” to say that “somebody has dementia” (lines 6-10). The patient is nodding along to this explanation, and the doctor then moves to more specific language – “with you it is quite tricky”. Peräkylä demonstrated in primary care that displaying uncertainty encourages patient questions, which suggests that the doctor is pursuing patient engagement in the diagnostic discussion (Peräkylä, 2005). It is successful in this case, and the patient responds with two latched tokens. While it is unclear whether the first part of the patient’s utterance is “right” or “why”, the second part “why” seeks further clarification as to the reason for this (line 11). The doctor explains further, and states that the patient is still “functioning at a very high level”. The questioning intonation, with the doctor leaning closer to the patient, invites agreement. The patient does not respond in the micro-pause but with the doctor’s mouth click and in-breath (start of line 15) he looks away with widened eyes and raised eyebrows, in a comic expression of disbelief. As the doctor laughs, she moves closer and gestures and smiles to the patient’s wife, and the patient exaggerates his disbelieving facial expression by stretching his mouth to the sides. The patient’s wife laughs, and the doctor starts to continue (lines 16-18). The patient looks at his wife and continues to joke (line 19), and is still smiling while the doctor continues. The doctor re-refers to examples of the patient’s symptoms that have been discussed in the assessment stages, providing an account of the diagnosis, which is another common way of elaborating upon the diagnostic information and encouraging patient response.

Extract 11 illustrates the potential difficulty of elaborating on the diagnosis to pursue a patient response. The doctor has changed the focus from the diagnosis to the wife’s report of the patient’s functioning, and it is the wife’s report that the patient has responded to rather than the diagnosis itself. This is also evident in extract 10 above, where the patient responds to the “early stages” aspect of the diagnosis. This is a phenomenon observed in

psychotherapy, where the slight shift in topic introduced by the psychoanalyst when pursuing patient responses can lead to a discontinuity in the patient's response from the content of the initial interpretation (Peräkylä, 2011). Doctors in memory clinics are oriented to the potential trouble caused by patients agreeing with certain aspects of the diagnosis (i.e. uncertainty of the diagnosis and downgrading of the diagnosis) that could lead to resistance to later treatment discussions. This is evident in the continued diagnostic discussion in extract 12 presented below. One minute and 52 seconds has passed: the doctor has completed her description of the difficulties the patient is experiencing when planning their travelling, and then her phone rings which she answers quickly but turns out to be a wrong number. She then feeds back the cognitive test results in detail, which were only discussed in overview ("you haven't done quite as well as three years ago") before the diagnosis delivery. The patient interrupts as she is doing so, asking if they will have the information in writing because he knows he will forget what he is being told. The doctor then continues with the diagnostic discussion, which is where the second part of this extract begins.

**(12) [P183\_H49 (part 2)]**

92 DR: um, tch (0.4) so you scored eighty eigh:t (.) back in  
 93 two thousand and twelve.=.h[hh ] (.) this time you  
 94 PT: [mm.]  
 95 DR: scored seventy six,  
 96 PT: °°that's right°°  
 97 DR: but it's a three year ga:p so:, (.) you know (.) I:,  
 98 (0.5) °°m- m-°° (0.6) tch (0.8) I would expect you to do  
 99 better than seventy six:, but with dementia I might have  
 100 expected you: to have a bigger drop.  
 101 (0.5)  
 102 DR: am I making sen[se?]  
 103 PT: [ ye]s.  
 104 DR: .hhh  
 105 PT: tha- yes.  
 106 DR: um tch (.) [so,]  
 107 PT: [so ] so the dementia is not °m hm°  
 108 [v- very serious.=is it?]  
 109 DR: [I- I hh .hh ] exactly I think what I'm





and the patient appears to be processing this information, signalling further realisation with an oh-prefaced receipt and explication of his understanding – “I see” (line 116). The doctor continues defining Alzheimer’s disease as a type of dementia after this extract finishes, before continuing to medication discussion.

As this extract shows, elaborations of diagnostic information can be lengthy, as the doctor pursues a response from the patient. The doctor in extract 12 chooses to follow her elaboration by directly exploring the patient’s understanding with an understanding check (line 102), which results in the patient actively participating in the discussion with questioning. Understanding checks are a common strategy to pursue responses from the patient, with many doctors checking understanding immediately after the diagnosis delivery, i.e. prior to elaboration of diagnostic information.

#### Understanding checks as pursuits of response

Extract 13 is an example of an understanding check used immediately after diagnosis to pursue a response.

#### **(13) [P66\_H03]**

1 DR: .hh so we thi- we think (.) we think y- the memory  
2 problems .h you have are caused by >w- °er wha- we-°<  
3 what we call .hh vascular dementia  
4 CN: °yeah that’s what I thought.°  
5 DR: °°ri[ght°°]  
6 PT: [ ye]a:h.  
7 (0.3)  
8 **DR:** hh .hh which i:s .hh so what- >do you¿ do you¿< have you  
9 ever hea:rd of the: (.) the wo:rd dementia before or¿  
10 (.)  
11 PT: >I say< I’ve bee:n before yeah there: (0.9) there-  
12 there- [ yeah I’ve been here bef]ore:, I: and  
13 CN: [yeah we have talked about it.]  
14 PT: [>you know< just] a  
15 DR: [yeah yeah. ]  
16 (0.5)  
17 DR: m.hhh so I mea:n, (.) dementia’s er is just a (.) >a-

18 a-< a wor:d for (.) for for (.) for the memor- memory  
19 problems and other problems of the thinking that that  
20 .hh u:m .hh uh >that you're experience< and we think the  
21 c- we think the cau:se of that is is is (.) basically  
22 (.) the blood sup[ply to the brain be]ing not as good as  
23 PT: [°ri::ght.° ]  
24 DR: i- it used [used to be. ]  
25 PT: [°we:ll it is°] the old age  
26 [like I said here] now  
27 DR: [yeah yeah yeah ]  
28 PT: [(heheh you know you've got-) ]  
29 CN: [well [it's m]ore [to do] with the st]roke Dad and the  
30 DR: [well, ]  
31 CC: [oh:, ]  
32 CN: [blood [circ]ula[tion that's] what it's do do with  
33 CC: [ ye[ah: ]  
34 DR: [mm. ] [yeah. ]  
35 PT: yeah:.  
36 DR: yeah.  
37 CN: °mhm°  
38 **PT**: oh I just ↑what can you: do just ahh heh heh heh carry  
39 o(h)n carry on and that [there's nothing:]  
40 DR: [well I think ] I think  
41 CC: no.  
42 **DR**: I think (0.4) I think one: wo- you're you're you're  
43 you're right actually >and I think the sort of< the- the  
44 best (.) the (.) the best advice I can give you is to  
45 (.) carry on: enjoying what (.) what you do actually

The patient's daughter responds to the diagnosis, with a confirmation of her expectations, while the patient opens his mouth, nods and then provides a minimal acknowledgement (lines 4-6). The doctor acknowledges the daughter's remark and turns to the patient, potentially starting to give a definition of dementia. However, he abandons that turn, potentially because of the strong recognition in the daughter's response, and instead asks "have you heard of the word dementia?" (lines 8-9). This directly checks the patient's understanding of the diagnosis. The patient responds immediately, nodding as he says he's "been before", gesturing outwards, but then appears to have some difficulty

completing the utterance, filling with the “yeah there” and gesturing more rapidly (lines 11-12). Gesturing can signal communication difficulties (Lavelle et al., 2013). The patient has been demonstrating word finding difficulties throughout the meeting, likely a symptom of his dementia compounded by English being his second language, and thus it takes a couple of restarts for him to formulate the sentence. This leads to the daughter responding for him in overlap in the second part of his turn (line 13), but the patient raises the volume of his voice to confirm “I’ve been here before” (line 12-14). This can be taken to mean the memory clinic, and thus could be an indirect way of demonstrating that he knew the diagnosis was a possibility.

The doctor acknowledges the daughter’s response in overlap with the patient (line 15), before giving a definition of dementia. This definition is similar to those that occur in the pre-diagnosis position (see Chapter 5), with a minimisation and formulation of dementia as a medical term “just a word” (line 17-18).

Additionally, he re-refers to the patient’s symptoms (lines 19-21), and the evidence from the brain scan (lines 21-24), thus accounting for the diagnosis. The patient had attributed his difficulties to old age in the test feedback stage, which he re-iterates at this point (lines 25-26). He starts smiling and then chuckling, indicating the delicate situation of attributing the brain scan results to a different cause than the doctor (Haakana, 2001). The doctor’s repeated “yeah” continuers (line 27) acknowledges the patient’s view point but indicates a shift to speakership (Jefferson, 2009), but the patient’s daughter instead interrupts the patient stating “it’s to do with the stroke” (lines 29-32). This medicalises his symptoms and rejects the patient’s attribution of his difficulties to age.

The nurse and the doctor confirm the daughter’s formulation (lines 33-34), and the patient responds with a lengthened, downward intoned acknowledgement token (line 35). The doctor and patient’s daughter pass up the opportunity to continue by also providing minimal acknowledgement tokens, and the patient elaborates (lines 36-39). He starts with an oh-prefaced response, thus holding his stance or at least claiming knowledge of his situation (Heritage, 1998). However, he abandons this and shifts the topic instead to negatively assessing the utility of the diagnosis in terms of getting treatment or help (lines 38-39).

Despite the remaining potential resistance on part of the patient, the doctor accepts this topic shift and moves on to discuss the future (lines 40-45). The doctor's emphasis that the patient can still have a positive outlook on the future ("the best advice I can give you is to carry on enjoying what you do"), is a common method of transitioning to the next stage of the meeting, and will be examined further in the next section.

Understanding checks therefore allow the doctor to explicitly pursue the patient response immediately after the diagnosis. Many doctors follow this with an elaboration containing a definition of the diagnosis, which can elicit further patient response.

#### *Asking the patient's perspective as pursuit of response*

Another method for doctors to pursue non-minimal patient response after the diagnosis delivery is directly asking for the patient's perspective on the diagnosis.

#### **(14) [P87\_H22]**

1 DR: so I think, (0.4) what you ha:ve (0.4) is an early form  
2 of Alzheimer's disea:se.  
3 PT: °°mhmm°°  
4 (.)  
5 DR: what do you think about tha:t  
6 (1.8)  
7 PT: I wouldn't think I had i:t,  
8 (0.8)  
9 PT: but u:m, (2.6) I'm hoping it's not a gra::ve thing,  
10 DR: I don't think that it is a grave thing  
11 PT: °°okay°°  
12 DR: some people don't like hearing it because, (0.6) e:r  
13 >because it< can be a scary thing sometimes,  
14 (0.4)  
15 DR: but I think what I'm saying toda:y is that we've got  
16 (0.4) you've been having these little problems over  
17 ti::me and now what we've been able to do is we've got a  
18 na:me for it we know what it i::s

19 PT: yes very goo:d  
20 DR: so generally- that I think that's good because it means  
21 that we, (0.4) everyone can be aware of i:t,  
22 PT: °mm°  
23 DR: so you can kno:w but also your family ca:n, (0.6) and  
24 also so that we can start to think about the right  
25 treatment for i:t

The patient responds minimally to the diagnosis (line 3). The doctor, after a slight pause, asks the patient's perspective – what she thinks “about that” (line 5). After a delay of nearly 2 seconds, the patient appears to directly reject the diagnosis (lines 6-7), albeit qualified as a display of her own opinion “I wouldn't think I had it”. The doctor nods and the patient, who has looked away at the floor after the diagnosis, then looks back up to the doctor and starts to respond further, then leaving a long pause before stating “I'm hoping it's not a grave thing”. This “*citing of hope*” (Beach et al., 2005, p900) illustrates optimism where the description of “a grave thing” shows a prior concern of the severity of the diagnosis. This statement also seeks reassurance from the doctor, which he provides – acknowledging and normalising the patient's fears using generalised language “some people don't like hearing it” (lines 12-13). The patient nods after “don't like hearing it”, but only blinks as a response at the pause (line 14). The doctor continues with a “*bright side telling*” of the news (Maynard, 2003a, p179), focussing on the positive aspects of having a label for the patient's “little problems” in leading to treatment (lines 15-18). By defining the diagnosis as a “name”, the doctor is also minimising its importance, similar to how doctors approach the diagnosis prior to delivery (Chapter 5). The patient accepts and positively assesses (“yes very good” line 19) this framing of the diagnosis, and the doctor moves on to talk about treatment and support, both for the patient and her family.

#### *Moving straight to treatment discussions with no pursuits of response*

The three cases where doctors move straight to treatment seem to reflect an alteration in the systematic pattern of dementia diagnosis. In each case the doctor asks the consent question prior to the diagnosis, which as discussed in Chapter 5 is a commonly used pre-diagnosis practice (as in extracts 3 and 4,

Chapter 5). However, in all three of these cases the patients do not provide the expected positive response, instead explicitly engaging in discussion with the doctor about the purpose of the diagnosis – i.e. whether they would receive treatment. These are the only cases in the dataset where patients do this: other meetings where the consent question is blocked are more similar to extract 4 (chapter 5), where the patient changes the subject rather than answering the question.

### (15) P38\_H23

1 DR: do you want me to talk to you about a diagnosis? would  
2 you like to know what I think the diagnosis i:s?  
3 PT: well is there a treatment for i:- for this?  
4 (.)  
5 PT: >am I< (0.4) am I going to be treated for it or is it  
6 just, (0.4) um, (0.6) for: information?  
7 DR: .tch .hhhh (0.8) it's partly for information there a:re  
8 there is so::me so::me (0.6) intervention we can offer  
9 you:  
10 (0.8)  
11 DR: would you like me to tell you about: what I think your  
12 diagnosis i:s,  
13 PT: yes  
14 (0.6)  
15 PT: ri[:ght.]  
16 DR: [ ok]a:y  
17 (0.6)  
18 DR: .hhh well the name that we gi:ve to:: people with  
19 progressive (0.6) memory impairment or cognitive  
20 impairment (0.4) is a condition called dementia.  
21 (0.6)  
22 DR: now dementia is (0.4) can be caused by a number of  
23 different (0.6) um causes (0.4) .hhh and I think (.) be:  
24 (.) cause of the changes we've seen in your sca:n (0.4)  
25 I think the most (.) likely cau:se (0.6) i::s (0.4) e::r  
26 is one of vascular dementia=I think that's the most  
27 likely diagnosis  
28 (0.8)  
29 DR: .hh no:w, (0.6) the::, (0.4) u::m, (0.4) in terms of

30 treatment we don't have treatment that can reverse  
31 (0.8) over this condition,

The doctor in lines 1-2 asks the consent question – if the patient would like to know the diagnosis. The patient's well-prefaced response projects an indirect answer (Heritage, 2015), and she asks if there is treatment, contrasting with the alternative that the diagnosis would be “just for information” (lines 3-6). The doctors' response shows some delay – it transpires that the patient has vascular dementia so she would not be able to have medication – but she says that there is “some intervention” (lines 7-9). The patient nods in line 10 and the doctors re-states the question (lines 11-12), with the patient now responding in the affirmative (lines 13-15). The doctor then goes on to deliver the diagnosis (lines 18-27), attributing the diagnosis of vascular dementia to the patient (through inference, as described in Chapter 5) in lines 23-27. The patient nods as the doctor finishes line 27 but passes up the opportunity for further response in the pause in line 28. The doctor, rather than elaborating or asking the patient an understanding or perspective question, moves straight onto treatment discussions.

The fact that all the cases where doctors move straight from diagnosis to treatment follow this pattern provides additional information as to why doctors normally appear to pursue a response after diagnosis. In these cases the patient has explicitly engaged in the possibility that a diagnosis from the memory clinic may lead to treatment or support prior to the diagnosis delivery. That the doctor does not pursue further input after the diagnosis suggests that this is sufficient input from the patient to progress to treatment discussions.

#### *Frequencies and Relationships in Doctor Pursuits*

Ninety-six per cent of doctors pursue responses to dementia diagnoses (Table 11). Forty one per cent of doctors pursue a response by elaborating on diagnostic information only. In over half (55%) of meetings doctors explicitly pursue a response to the diagnosis using perspective or understanding check questions.

<b>Doctor Pursuit of Response</b>	<b>Frequencies</b>
Elaboration of diagnostic information	33 (41%)
Understanding check	29 (36%)
Perspective Questions	16 (19%)
Straight to treatment discussions	3 (4%)

**Table 11: Frequencies of types of pursuit of response**

As discussed above, in three of the meetings doctors progressed immediately to treatment discussions after the diagnosis was named with no pursuit of a patient response. In 40% of meetings more than one type of pursuit of patient response was used.

<b>Content of Elaboration of Diagnostic Information</b>	<b>Frequencies</b>
Prognosis	42 (52%)
Medical definition of dementia	24 (30%)
Deliver sub-type of dementia	22 (27%)
Re-reference symptoms	18 (22%)
Downgrade severity	12 (15%)
Make uncertainty explicit	11 (14%)
Re-reference evidence from testing	10 (12%)

**Table 12: Content of elaboration of diagnostic information**

The content of the elaboration of diagnostic information was also quantified to illustrate what kind of information doctors conveyed to the patient in this position (Table 12). Many doctors covered more than one topic when elaborating on the diagnosis. The prognosis of dementia, that it is degenerative, was highlighted in the diagnosis discussion in just over half the meetings. Other doctors elaborated on the diagnosis by defining dementia or specifying the dementia subtype. There were 34 (42%) meetings where the elaborations included at least one of the following: re-referencing the symptoms and evidence, making uncertainty of the diagnosis explicit, and downgrading the severity of the diagnosis. As discussed above, these behaviours are indicative of doctors pursuing agreement.



### Summary

Doctors in memory clinics pursued patient response to the diagnosis prior to progressing to treatment and support. They elaborated on the diagnosis with information about dementia, and explicitly checked the patient's knowledge of dementia and perspective. Often they used a combination of these strategies to elicit responses. Elaborations consisted of specification of the dementia subtype, explanations of the cause of the patient's dementia, re-referring to the patient symptoms or evidence from the testing and downgrading the severity or certainty of the diagnosis. Prognosis was only discussed in this position in half of the meetings. Doctors moved straight to treatment after diagnosis in instances where patients had already engaged in discussions about treatment within the diagnosis delivery sequence.

### **Patient Later Responses to Diagnosis**

The majority of doctor pursuits of patient responses to the diagnosis are successful in eliciting a non-minimal response prior to progressing to the treatment phase. While there was no explicit resistance in the initial responses to the diagnosis, many patients showed resistance to the diagnosis once the doctors pursued a response. Some patients reiterated their age as the main reason for their memory difficulties, as with the patient in extract 13 (page 173) above. Other patients invoked their ability to function, or gave reasons why their symptoms are not bad enough to be called dementia. Some patients worked to close down and avoid further discussion.

### **(16) [P109\_H41]**

- 1 DR: well, (0.3) it looks like you:, have probably got  
2 Alzheimer's disease.  
3 PT: °oh ri:ght yeah.°  
4 (.)  
5 DR: you don't have any idea what that might amount to?  
6 (4.2)  
7 PT: tch

8 (4.4)

9 PT: I don't ↑know: >i- uh<

10 DR: have you heard [of it] before?

11 PT: [uh; ]

12 **PT:** ye:s and uh (1.1) hhh >you know< (.) >you think< well  
 13 what happened °>to me<° many years ago:, (0.5) it's gone  
 14 it's history I >don't really want to know in ↑any case<  
 15 (0.3)

16 DR: okay.

17 (0.8)

18 DR: .hhh

19 PT: as long as I've got my: (.) sons.  
 20 (0.4)

21 DR: okay.  
 22 (.)

23 **DR:** .hh there's something else I'd like to a:sk you  
 24 though.=before we move on to talk about the Alzheimer's  
 25 disease and that's abou:t how much alcohol you  
 26 dri:nk.=now:.  
 27 (.)

28 PT: no: I don't.

The patient responds to the diagnosis with a news receipt, showing registration of the diagnostic news (line 3). The “oh” demonstrates change of state (Heritage, 1984), and double token responses (as in “right, yes”) are often used in the pre-closing position (McCarthy, 2003), meaning that, especially as this is also a news receipt format which discourages elaboration, the patient’s response is already demonstrating reluctance to continue with the diagnosis discussion. The fact that the doctor pursues further response, despite the initial response being non-minimal, provides further evidence that doctors are seeking more than an acknowledgement of the news before moving on to treatment. The doctor uses an understanding check, a negatively polarised yes/no interrogative (line 5), presupposing the person will respond with a negative answer.

There is nearly a 7 second pause with just a mouth click from the patient before she answers. She states that she does not know, and is moving her mouth as if

to continue when the doctor reformulates her question, specifically asking if the patient has “heard of it” (line 10). The patient answers with an emphasised “yes”, and after a pause and more hesitation, including a reference to something that has happened in her past (which is unclear from the interaction thus far), she says that it is “history”, and she “doesn’t want to know in any case” (lines 12-14). She is not looking at the doctor throughout this turn, again indicating an avoidance of the diagnosis discussion. The doctor acknowledges her preference, and after a pause starts to continue, when the patient elaborates on her statement, indicating that her sons are all that matter to her (16-19). The doctor acknowledges this again and shifts the topic to questioning whether the patient is drinking alcohol (lines 21-26), and after this moves on to treatment and support discussions.

Other patients do respond to the diagnosis, usually with questions or statements about dementia. These questions and statements, while encouraging further discussion, are non-valenced, in that they do not contain assessments that would indicate how the patient feels about the diagnosis.

### (17) [P42\_H50]

1 DR: .hh so it might be >that there's< (.) there's a c couple  
 2 of processes going [on that's caus]ing the  
 3 PT: [mm::. ]  
 4 DR: dementia.=there's .h a bit of Alzheimer's disease and a  
 5 and a bit of the hardening of the ar[teries >a sort of<]  
 6 PT: [mm:. ]  
 7 DR: a (.) a [mixed] picture.  
 8 CN: [mm. ]  
 9 (0.8)  
 10 **PT:** and is it likely to get (.) worse:?  
 11 DR: .h on the whole I think it will:.  
 12 CN: mm  
 13 PT: over a:  
 14 DR: bu-  
 15 PT: short period >a long< period?  
 16 DR: we can't say.  
 17 PT: n[o: er ]  
 18 CN: [right.]

19 DR: I mean usually i- it's over a period of a quite a few  
20 years.  
21 PT: mm::.  
22 CN: °°m°°  
23 (0.8)  
24 DR: >and of course< .hh there are things: you can do: which  
25 can help.  
26 PT: yes.

Prior to this extract the doctor delivered the diagnosis, with a minimal response from the patient. The doctor had discussed the cognitive test results prior to the diagnosis, but after the diagnosis shows the patient the brain scan for the first time to explain the diagnosis subtype, which he explains as being “a mixed picture” of Alzheimer’s and vascular dementia (lines 1-7). The patient and his wife show engagement in this explanation with minimal continuers (lines 3, 6, and 8). The doctor pauses once he has finished his explanation and nods at the patient, inviting a response, which leads to a question about prognosis (line 10). The doctor confirms the patient’s understanding “likely to get worse”, albeit in a mitigated manner with “on the whole” and “I think”. The patient presses for more information (line 13-15), and the doctor emphasises the uncertainty of the prognosis, stating an optimistic projection of “quite a few years” (lines 19-20). After minimal but emphasised acknowledgement from the patient, and quiet acknowledgement from his wife (lines 21-22), the doctor shifts to a good news exit about treatment options, which the patient responds to (lines 24-26). This pattern occurs in the vast majority of cases where patients respond to pursuits with questions or statements: the doctors will answer or respond to the patient input and, if the patient does not elicit further response, move directly to treatment discussions.

Patient questions thus often demonstrate some prior knowledge of dementia, and thus show engagement in the diagnostic discussion. Patients can also engage in the discussion through non-valenced statements about their condition or symptoms (e.g. *“the last couple of years I thought to myself I can’t remember things”* P50\_H43). These questions and statements show some level of alignment with the diagnosis and maintain a stoic stance with no negative assessment of the news, as is the norm in diagnosis discussions.

Some patients do demonstrate explicit negative responses. In many of these cases, patients demonstrate an understanding of the nature of dementia in its later stages, and a desire not to be that way. The following extract is presented in two parts to demonstrate first how the patient's response to the diagnosis develops from minimal to negative after pursuit from the doctor, and then how the doctor responds to the patient's response.

**(18) [P67\_H03 (part 1)]**

1 DR: .h so >I mean we-< (0.3) we think (.) on the basis of of  
2 >of all< that (.) that (.) .hh u:m (.) that your memory  
3 problems are caused (0.4) uh (.) by: an illness called  
4 Alzheimer's disease.  
5 PT: °oh:..  
6 (.)  
7 DR: °°okay .hh°°  
8 (0.3)  
9 DR: uh mi:ldʒ  
10 (0.3)  
11 PT: [yea:h]  
12 DR: [but ] that that's what we think >the the< the cause  
13 i:s.  
14 (0.7)  
15 PT: ↓oh: right.  
16 (0.3)  
17 DR: okay .hh (1) have you- >have you< heard of (.) have  
18 [haveʒ ]  
19 PT: [°oh yeah° ]  
20 CN: [her brother] had it  
21 DR: yeah:..  
22 (.)  
23 DR: and what what do you: (.) what do you know about  
24 Alzheim[e[r's diseaseʒ]  
25 PT: [well my bro-] my brother had it.  
26 (0.3)  
27 DR: °mm:°  
28 PT: my brother had that.  
29 DR: ri:ght.

30 (1.5)  
31 CN: [°is-°]  
32 CC: [so- ]  
33 **PT:** and I'd ha:te to get like it.  
34 (.)  
35 PT: °m m°  
36 (.)  
37 PT: I really would.  
38 (.)  
39 DR: [°mhm°]  
40 **PT:** [I'd ] rather be dead.  
41 DR: °°m°°  
42 CC: °mm:°  
43 PT: I would.  
44 CC: mm:.  
45 (2.1)  
46 CN: °mm°  
47 (1.4)  
48 CN: .HH  
49 (19.4) *(DR & CC get up to get tissues, DR hands the*  
50 *tissues to PT & CR, who are both crying)*

In this extract the patient initially responds to the diagnosis minimally and quietly, with the “oh” indicating change of state and thus recognition of the news (Heritage, 1984) (line 5). Again, despite this being a non-minimal response (in that it is a news receipt rather than an acknowledgement token), the doctor elaborates on the diagnosis, indicating that a more extended response is being pursued. He begins by downplaying the severity (“mild” line 9), with an upward intonation encouraging patient response (Stivers and Rossano, 2010). The patient provides acknowledgement (line 11), and the doctor re-states the likely cause of her memory problems, without the diagnostic term but with “that” referring back to “Alzheimer’s disease” (line 12). Again the patient responds with a news receipt – “oh right” – which passes up the opportunity to respond further and discourages further elaboration (line 15). The doctor uses an understanding check – “have you heard of..?” – with some delay and re-starts (line 17-18). The patient’s response – “oh yeah” – is oh-prefaced, indicating a problem with the question (Heritage, 1998) and emphasising the response (line

19). The reason for this design is evident in the daughter's answer to the question, which confirms the patient's close experience of dementia, having had a brother with the condition (line 20). The doctor's acknowledgement ("yeah") suggests some prior knowledge of this, which he is likely to have obtained from the initial assessment (line 21).

The doctor however pursues further response with a more specific question about what the patient knows about Alzheimer's disease (lines 23-24), and the patient re-iterates her daughter's statement twice (lines 25 and 28). The doctor acknowledges this and pauses, and the patient's daughter and the nurse both begin utterances but stop as the patient elaborates. The patient offers a strong negative assessment of her brother's dementia, saying she'd "hate to get like it" (line 33). After a pause the patient continues with her negative formulation, emphasising her prior statement and upgrading, stating "I'd rather be dead" (lines 37-43). The patient at this point has started to cry, and her daughter also has tears in her eyes. The doctor and nurse move to get tissues and there is a pause of nearly 20 seconds before the patient's daughter asks about medication, which is where the next extract begins.

### (19) [P67\_H03 (part 2)]

51 CN: is there:: anything li:ke is ↑there medica:tion you can  
52 get?  
53 (0.9)  
54 DR: ↑there- yes there i::s, (.) um, (.) >I mean [I< I- I]  
55 CC: [°mm:° ]  
56 DR: ↑think (.) hh .hh (0.7) I- (0.8) >I mean I've given it<  
57 a (.) a ↓na:me,  
58 (0.7)  
59 DR: I:: >I mean I-< (0.3) I think, (0.8) >the important< (.)  
60 thi:ng to say:: i:s (0.6) tha:t (0.6) we ↑do: >you ne-<  
61 w- we ↑do think it's it's mi::ld,  
62 PT: yeah.  
63 (0.3)  
64 DR: .hhh an:d (0.3) as I say:, (.) I mean it (0.5) on lots  
65 of the test (0.4) you did well.=>so it's< .hh it's not  
66 th[at ]  
67 PT: [°m°°]

68 (.)

69 PT: no: it's not ba[:d no. no. ]

70 DR: [not >that there's< >>problems all the<<]

71 you know there's particularly the memory that that

72 that's .hhh that that seems to be a problem.

73 PT: mm:. .

74 (0.5)

75 **DR**: ↑I:: (0.3) do:n't thi- >I mean I< can't guarantee this

76 but I don't expect things to (0.5) to progress (0.6)

77 quickly::?

78 PT: no:,

79 (.)

80 **DR**: I- I mea:n (0.7) I'm hoping things will remain stable

81 for (0.3) for year:s rather than (.) than months or or

82 or [wee:ks] so, .hh >I mean I< ↑think that's really

83 PT: [yeah. ]

84 DR: important (.) to say: we- we have (.) given it a na:me

85 (.) tod[ay:.]

86 PT: [ ye]ah:

87 **DR**: .hh but I would- (.) you know: I- (.) I'd like you to

88 (.) >kind of< (0.3) just carry o:n prettly much (.) as

89 [nor:ma:l ]

90 PT: [as normal] ye[ah ]

91 DR: [.hh] >and- and-< and focus on doing the

92 things that you: (0.8) enjoy:,

93 PT: yeah, (.) [yeah ↓m.]

94 DR: [doi:ng, ] and in fa:ct (1.1) keeping a:s

95 (0.4) mentally and physically active as possible (0.3)

96 is is part of the treatment really

The doctor's response to the patient negative response, while slightly more elaborate than other examples, includes some key features of doctor management of patient responses to the diagnosis. The patient's daughter has asked about medication (lines 51-52). The doctor confirms that this is available, but makes an effort to address the patient's concerns prior to progressing to treatment discussions (lines 54-57). The difficulty in delaying the progression to the next stage of the meeting and instead providing an adequate response to the patient's emotional response is evident in the doctor's numerous delays and



restarts. He then continues with a series of statements about the diagnosis, encouraging agreement from the patient after each statement. This response to crying has been demonstrated in other institutional settings, and continues the progression of the interaction in a way that expressing empathy or sympathy may not (Hepburn and Potter, 2012).

The doctor's first approach is thus "*subordinating the label*", minimising the importance of the diagnostic term to encourage appropriate responses (Gill and Maynard, 1995, :23). This is similar to how doctors design the diagnosis delivery itself, as illustrated in extract 14 (page 176). The patient acknowledges this with a nod (line 58), and the doctor moves to his second strategy: the re-emphasis of the "mild" aspect of the illness (lines 59-61). The patient acknowledges this with a minimal "yeah" (line 62), and the doctor elaborates, using the evidence from the test results to support the mild nature of her illness (lines 64-66). This is designed as a laudable event proposal (Maynard et al., 2016) – on "lots of the test" the patient "did well" – and thus encourages agreement. The use of the evidence in managing the patient's emotional response, where it has been shown previously to manage resistant patient responses (Peräkylä, 2005), shows the flexibility of the test evidence as a resource for doctors. The patient shows strong alignment, completing the doctor's turn (line 69), and thus demonstrating an effort to control her negative emotional response and align with the doctor's optimistic portrayal.

The doctor then discusses the prognosis of dementia, which the patient has displayed knowledge about due to her experience with her brother. He uses another common strategy in the management of patient responses: an optimistic projection of the patient's future ("years rather than months" lines 80-82). He downplays the effect this will have on the patient's life, emphasising that the patient should "carry on pretty much as normal" (lines 87-92). The patient acknowledges this (lines 90 and 93). Optimistic projections often indicate a shift from one topic of discussion to another (Jefferson, 1980), which is the case in this example as the doctor proceeds to discuss the treatment and future planning (lines 94-96).

These optimistic projections or bright side tellings are thus used as good news exits from the diagnosis (Maynard, 2003a), and are very frequent in the transition from diagnosis to treatment discussions. They are a method of dealing with emotional responses, but are also commonly used in resistant responses, such as extract 13 (page 173), and in response to patient questioning, such as extract 16 (page 181). Optimistic projections are used even when patients do not respond to the diagnosis, despite some pursuit from the doctor.

**(20) [P118\_H40]**

1 DR: the- (.) the commonest cau:se of a: mild memory problem  
2 like thi:s (0.4) is probably something like Alzheimer's  
3 disease  
4 (0.5)  
5 DR: and I suspect (.) that that is what's going on.  
6 PT: °mhm.°  
7 (.)  
8 DR: that (.) that you probably ha:ve (.) ear:ly Alzheimer's  
9 disea:se,  
10 **(0.6)**  
11 DR: which is a: a disease in the brai:n which affects  
12 memory.  
13 **(1)**  
14 **DR:** .pt um .h (0.8) a:nd (.) I think that's (.) it's good  
15 to:: star:t thinking about that as a possibility, (.)  
16 because: there are some, (.) things that we can try to  
17 do::, (0.3) medications that we can [try]:: (.) which  
18 PT: [mm ]  
19 DR: can help to:, (0.6) slow dow:n the progression of- of  
20 the memory problem.  
21 (.)  
22 DR: tch .hh  
23 **PT:** ah: that's good.

The patient responds initially to the diagnosis with a small nod, and continues nodding as the doctor continues with his delivery, responding with a quiet acknowledgement token as he completes his turn (lines 1-5). The diagnosis is

delivered through inference (see Chapter 5), and as a pursuit of response the doctor changes the format to a direct diagnosis (lines 8-9). The patient responds with a very small nod, and the doctor pursues further with a definition of dementia, and another pause (lines 10-13). The patient again passes up the opportunity to speak (line 13), and the doctor thus progresses to a good news exit – explicitly assessing the diagnosis as “good” (line 14), because the patient will be able to start medication. He uses “we” in this assessment, further encouraging the patient to take part in the discussion (line 16). The patient does not respond at the end of the turn, and the doctor clicks his mouth and breathes in as if to continue, when the patient finally issues a non-minimal response, aligning with the doctor’s good news assessment (lines 21-23).

The methods that doctors use to move the medical agenda forward from diagnosis to treatment discussions are therefore similar across the meetings, using optimistic projections of the future and minimising the impact of the diagnosis. These strategies occur regardless of whether the patient responds to the pursuit with questioning, negative responses, resistance, or even if they do not respond beyond non-minimal acknowledgement. An interesting feature of these good news exits is that, although they implicitly refer to the fact that dementia is a progressive illness, prognosis is not always explicitly referred to. While in many cases patients demonstrate knowledge of the prognosis of dementia, often indirectly through mentioning a family member who has the condition (or asking if it will progress for example), doctors do not often explicitly refer to the fact the patient’s symptoms will get worse. When prognosis is discussed, it generally occurs in the framing of an optimistic projection, as the doctor moves out of the diagnosis discussion in to the treatment stage.

#### *Frequencies and Relationships in Patient Later Responses to Diagnosis*

Patients were more likely to respond to the diagnosis if they were asked questions on their perspective or understanding, rather than when doctors only elaborate on diagnostic information ( $X^2(2, N=81)=6.497, p=0.026$ ) (more detail in Appendix E 4).

Table 13 illustrates the nature of patient responses after pursuits. Just over a third of patients (36%) did not participate in dementia diagnosis discussions beyond minimal acknowledgement token after doctor pursuits, although 7 of these had responded extensively initially (27% of patients do not provide more than a minimal acknowledgment token at any stage of the diagnosis discussion). Just under a third of patients (30%) responded to pursuits with

<b>Patient Responses after Pursuit</b>	<b>Frequencies</b>
None or minimal <i>Initial Response none/minimal</i>	29 (36%) 22 (27%)
Question or non-valenced comment <i>Initial response none/minimal</i>	24 (30%) 14 (17%)
Resistant <i>Initial response none/minimal</i>	13 (16%) 12 (15%)
Negative <i>Initial response none/minimal</i>	12 (15%) 6 (7%)
Off-topic <i>Initial response none/minimal</i>	3 (4%) 3 (4%)

**Table 13: Frequencies of patient responses after pursuit**

questions or non-valenced statements about symptoms or the diagnosis. Sixteen per cent of patients explicitly demonstrated resistance, and 15% showed negative responses. Three patients responded with a topic shift, all moving the topic to other physical conditions. In 35 of the 52 cases where patients responded extensively after doctor pursuit (67%), they had not responded initially to the diagnosis.

There was a trend in how patients initially respond to diagnoses and how they respond after the pursuit from the doctor ( $\chi^2(28, N=81)=33.191, p=0.071$ ) (more detail in Appendix E 5). Patients who withhold responses initially to the diagnosis were more likely to resist at later stages in the discussion, with none of the patients who responded extensively to the initial diagnostic turn later showing resistance. Furthermore, a larger proportion of patients who respond initially with a marked “mm” (so with changing intonation or emphasis), resisted than those with other minimal verbal or non-verbal responses (55% versus 5-22%).

Half of the patients who ultimately negatively assessed the diagnosis had initially responded minimally or non-verbally, and therefore explicitly passed up the opportunity to speak. Additionally, four of the patients had responded initially with news receipts, thus discouraging further discussions (Maynard, 1997). Only 2 of the patients who initially responded negatively extended their negative responses after doctor pursuit. This demonstrates the preference for stoic responses to diagnoses, with patients trying to not respond negatively immediately on hearing the diagnosis.

Patients who initially responded to the diagnosis with unmarked “yeah” or “mm”s had similar patterns of later responses – potentially indicating no difference between their stances as minimal acknowledgement tokens. Off-topic later responses, showing explicit inability to process and respond appropriately to the diagnostic information, occurred only after minimal or no initial responses from patients.

### Summary

While the majority of patients initially respond minimally to the diagnosis, doctor pursuit of responses led to a range of responses. Patients were more likely to provide non-minimal responses if doctors explicitly questioned their perspective or understanding. Patients can show resistance through attributing their symptoms to age or actively avoiding further discussion. They can participate in the diagnosis discussion through questioning or statements on symptoms, or by negatively assessing the diagnosis.

Minimal initial responses were linked with different types of later responses: marked minimal responses were more likely to be followed by resistance, and unmarked minimal responses were more likely to lead to negative, off-topic, or further minimal responses.

Doctors managed the different types of patient non-minimal responses very similarly, minimising the severity of the dementia and downplaying the effect the diagnosis will have on the patient’s life. Should the patient not respond to the attempts to pursue a response, doctors will eventually abandon pursuing a response and move on to the next stage of the medical agenda. Optimistic

projections of the patient's future or diagnostic trajectory were used to shift from diagnosis discussions to treatment discussions, regardless of how the patients responded to the diagnosis.

## **Discussion**

Patients generally respond initially to dementia diagnoses with minimal acknowledgement tokens, non-verbal acknowledgement gestures, or with silence. Even when patients responded with non-minimal responses, their initial responses were still restrained, generally indicating the newsworthiness of the diagnosis rather than explicitly demonstrating the patient's perspective. In nearly all meetings, the doctors pursued extended responses from patients, either through elaboration of the diagnostic information, or perspective or understanding questions, or both. Elaborations contained more medical information about dementia, such as the cause or the subtype, or elements designed to minimise the diagnosis, such as downplaying the severity or the certainty of the diagnosis. When doctors did not pursue a response it was because patients had engaged in treatment discussions prior to diagnosis. After pursuits of responses from the doctors, the majority of patients responded more extensively to the diagnosis. Resistance and negative responses to the diagnosis increased from the initial response, and patients asked questions about dementia, for example about its progression. Doctors ended diagnosis discussions using optimistic projections about the patient's future, which shifts the focus to the treatment stage.

As discussed in the introduction, it is typical for patients to respond minimally to diagnosis delivery, both in primary care when diagnoses are usually treatable, and in serious conditions such as cancer or HIV. Therefore, that nearly three quarters of patients respond minimally or not at all to dementia diagnoses is not surprising. However, the fact that patients with lower cognitive test scores were more likely to respond non-minimally to the diagnosis was interesting, and may be an indication of a loss of inhibition that can occur in people with dementia (Smith and Buckwalter, 2005).

While the patients' initial responses to dementia diagnoses followed patterns described in the literature, the near constancy of doctor efforts to pursue a response contrasts with what has been reported in other settings. This was firstly illustrated in the common use of direct delivery formats, discussed in Chapter Five to be used more often with people with higher cognitive impairment, which was found in the current analysis to be more likely to lead to non-minimal responses to diagnosis. Additionally, higher levels of cognitive impairment were found to be associated with non-minimal responses. The association between cognitive impairment, direct diagnosis delivery formats, and non-minimal responses needs to be explored in multivariate analyses to come to a conclusion as to the nature of these relationships. However, it appears that direct deliveries are potentially an effective method of encouraging patient response with people with cognitive impairment.

Doctor priority to elicit patient non-minimal responses was most clear in the pursuit of response after diagnosis. As discussed above, diagnosis delivery sequences described in the literature typically end with patient minimal acknowledgement and immediate progression to treatment discussions (Robinson, 2003a). Stivers (2005) reported that in primary care doctors do not pursue patient responses to diagnoses. This also occurs in secondary care diagnosis discussions, with reports of doctors in oncology avoiding extended responses so that they can complete their clinical tasks (Yoon et al., 2015, Maynard, 2003a).

Maynard describes two exceptions to this rule (Maynard, 2003a). In one HIV clinic counsellors specifically pursue patient negative emotional responses, because they argue that if the patient does not respond emotionally to the diagnosis, they will "*avoid carrying out the healthcare regimens necessary to the prolongation of health and life*" (Maynard, 2003a, :194). As discussed before, pursuits of responses can also occur with parents of children being diagnosed with developmental disabilities, as a "*remedial bid to attain agreement*" (Gill and Maynard, 1995, :20). Doctors follow the diagnosis by providing further information and questioning in order to manage any disagreement and ensure the doctor and parent share a common understanding of the child's diagnosis and its implications.

However, the aim of doctor pursuit of patient responses in memory clinics is less clear than these examples. Pursuits can contain minimisation of the diagnosis through emphasising the mild nature of the patient's dementia or the uncertainty involved in making the diagnosis. This is similar to how doctors in developmental disabilities clinics aim to achieve diagnostic agreement by characterising the condition as something that the parent will agree with. As discussed in the previous chapter, this may be a reflection of doctors trying to maintain a positive outlook for the patient, which patients themselves report as a priority (Wolverson et al., 2010). However, when patients in memory clinics respond specifically with the downplaying, or the portrayal of the diagnosis as uncertain, doctors change the focus back to the diagnosis in order to ensure recognition that the diagnosis has been made. Additionally, 58% of the diagnostic elaborations consist only of medical information such as naming the subtype or showing more detail from the brain scan, without minimisation or mitigation (for e.g. extract 9 (page 166) and 19 (page 187) above). These types of pursuits are thus not as explicitly oriented to encouraging agreement as in other settings. Similarly, questioning patient knowledge of dementia ("have you heard of that?") or perspective on the diagnosis ("what do you think about that?"), are open questions that generate a variety of responses, and thus do not appear to be directly designed to manage resistance.

The fact that doctors do not seem to be aiming for a particular type of patient response beyond a non-minimal response is supported by how the interactions unfold after the patients have responded. Doctors respond to all types of non-minimal response by moving the medical agenda forward to treatment discussions. An example of this is extract 13 (page 173), where the patient repeatedly avoids acknowledgement of his diagnosis, instead stating "oh what can you do? Just carry on." The doctor does not pursue agreement, but follows the patient's topic shift to treatment. This topic shift after extended responses occurs not only after resistance, but also when patients respond to diagnosis discussions, such as in extract 17 (page 183) and extract 14 (page 176), or pass up any opportunity to respond extensively, such as in extract 10 (page 167). The regularity of this progression to treatment after patient responses is also evident in the difficulty the doctor shows in halting the shift when



addressing the patient's strong negative response to the diagnosis in extract 19 (page 187).

Doctors do not therefore appear to be pursuing either displays of understanding or emotional processing before progressing to treatment discussions. One explanation for this could be due to the nature of dementia. Clinicians in HIV and developmental disabilities settings are aiming for emotional engagement and agreement in order to ensure the patients will persist in long-term engagement with medical and support services (Maynard, 2003a). However, dementia is a terminal illness, most often developing in later life, and even with medication people with dementia will experience worsening memory and a degenerating ability to understand the world around them. It may therefore be the case that doctors do not view explicit agreement or emotional processing as much as a priority as in other diagnostic settings where patients need lifelong adherence with healthcare services. The necessity to demonstrate explicit awareness of receiving a dementia diagnosis has been explored in terms of patient experience in the literature: with some suggestion that explicit knowledge of a diagnosis of dementia, without the appropriate coping mechanisms in place, may cause lower mood (Clare et al., 2006).

However, if it is the case that doctors are not aiming for patient agreement or emotional processing of the diagnosis, why are doctors pursuing responses to dementia diagnoses? It could be that doctors are compensating for the impact dementia will have on people's language processing and production. Studies show that some people with dementia will compensate for difficulties processing others' talk by displaying agreement regardless of content (Davis and Guendouzi, 2013, Sugarman et al., 2007). Therefore, even though minimal responses to diagnosis are common in all medical settings, doctors cannot assume understanding of the diagnosis with minimal acknowledgement tokens from people with dementia. Additionally, it can take more time than usual for a patient with dementia to process they are receiving a diagnosis, and elongating the diagnosis discussion provides for this. Doctors may therefore be pursuing non-minimal responses not necessarily to judge acceptance or emotional impact, but instead to ensure sufficient acknowledgement of the diagnosis to enable smooth progression to treatment discussions. If this is the case, it

appears that the nature of the patient's response is not important, and agreement is not a requirement. This is supported by the fact that 27% of patients do not respond beyond minimal acknowledgement of the diagnosis – initially or after further pursuit by the doctor – and in these cases doctors will move on to treatment discussions regardless, similar to primary care or other settings where pursuit is unusual.

However, the majority of patients display a response to the diagnosis after pursuit, and there are a wide variety of responses to dementia diagnosis. Patients demonstrate explicit resistance, negative assessment of the diagnostic news, as well as questions about and comments on the diagnosis. That doctors pursue non-minimal responses, and that these pursuits were successful for the majority of patients, enabled an analysis of the link between initial responses and the nature of later non-minimal responses. The potential meaning of initial responses has been discussed in previous studies of patient responses to diagnosis, but not extensively explored (Peräkylä, 2005, Heath, 1992). In the memory clinic data, the relationship between how patients responded initially and how they responded after pursuits were particularly interesting with minimal or non-verbal initial responses. The number of different types of minimal responses in the data was too small to demonstrate strong associations. However, it appears that marked minimal responses (with intonation or stress changes e.g. “mhm?” or “mm hm.”) were indicative of a more extensive patient initial response than unmarked tokens: patients using these responses were more likely to later resist the diagnosis. Additionally, the non-verbal or minimal unmarked acknowledgement tokens as a response to dementia diagnoses, as well as news receipts that discourage further elaboration, often led to negative responses. This supports Maynard's description of stoicism as a response to bad news where the recipient is the person affected: people withhold responses in order to encourage “*proposals of remedy*” (Maynard, 2003a, :152), which in the clinic setting will be treatment discussions. However, if the doctor does not immediately progress to treatment, and instead pursues a more extended response, the alternative, usually repressed, response to stoicism – “*flooding out*” of emotions (Maynard, 2003a, :151) – becomes more likely.

While there were only three meetings where doctors do not pursue a response – the similarities between these cases was striking. The fact that these three patients were the only patients that engaged in treatment discussions in the pre-diagnosis location gives an indication that doctors may be trying to get patients to engage in the diagnosis precisely so that they engage in treatment discussions. This is also reflected in how doctors manage patient extended responses to diagnosis. Focusing on hope and optimistic framing of outcomes has been often reported in diagnosis discussions of serious conditions, particularly as a method to shift from diagnosis to treatment discussions (Leydon, 2008). As demonstrated by the doctor in 19 (page 187), when patients show negative emotional responses to the diagnosis, doctors will respond by minimising the importance of dementia as a label, downplaying the effect that dementia will have on their life, and giving optimistic projections of their future. This also occurs in response to resistance (as demonstrated in extract 13, page 174), and optimistic projections are also used when patients only respond non-minimally (e.g. extract 20, page 190). The positive link that doctors are making between receiving a diagnosis and receiving treatment or support that will benefit them suggests that this is the message that doctors are aiming to portray in diagnosis delivery. That optimistic projections are so common, but the prognosis of dementia, i.e. that it is a degenerative condition, is only explicitly mentioned in half of the diagnosis discussions illustrates that many doctors are avoiding the negative aspects of dementia. The prevalence of this minimisation and positive framing of the diagnosis further indicates that this is a tactic not specifically to reassure patients, but a strategy to characterise dementia in a certain way prior to treatment discussions.

This optimistic framing of diagnosis is unsurprising. It is part of our social world that interactants are consistently aiming to maintain “*the benign order of everyday life*” (Maynard, 2003a, :198). Thus, just as bad news is delivered very cautiously, it also requires palliative treatment before conversation can move to other topics. This has been shown to be common throughout medical settings, with doctors adhering to a “*principle of optimisation*” where the preferential outcome for patients is always positive (Heritage, 2009, :14). Furthermore, research has been conducted into how patients wish for diagnoses to be delivered, and a balance of hope and honesty is important for coping (Mastwyk

et al., 2014). It is therefore common in all diagnostic settings for doctors to highlight the positive aspects of receiving a diagnosis, such as access to support or treatment or likelihood of recovery, over negative consequences, such as poor prognosis and side effects of medication (Leydon, 2008). However, this has been shown to lead to misunderstandings of diagnoses and their consequences, both in dementia and other clinical settings (Leydon, 2008, Yoon et al., 2015, Dooley et al., 2015).

As highlighted in the literature review (Chapter 2), there are two aspects specific to dementia that may make the reliance on optimistic communication of the diagnosis particularly troublesome. The first is the effect of cognitive impairment on the processing of the diagnostic interaction. As Leydon describes in oncology, if doctors immediately follow bad news with good news, patients may disregard the bad and thus have unrealistic treatment expectations (Leydon, 2008). For people with dementia, whose impaired short term memory difficulties will impair their information processing, following bad news with good news will make this even more likely (Jones et al., 2016, Bayles, 2003). The second aspect is related to the first, which is that the patient's cognitive impairment, and thus their difficulty in understanding, is going to get worse. There is no cure for dementia, and the medication is not always effective (Bullock et al., 2005). As discussed in the introduction to this thesis, the main aim of increasing dementia diagnosis rates, and for ensuring they occur at early stages of the illness, is to allow people with dementia to plan for their future while they are still able to do so. Therefore, any misleading information as to the progression of the illness may lead to patients and their families not putting support in place in a timely fashion. The repercussions of this are reflected in the patient interviews collected for the ShareD study, where patients showed confusion as to whether their illness would get worse and when this would happen (Xanthopoulou and McCabe, 2016).

In conclusion, doctors in memory clinics appear to be pursuing patient responses after delivering dementia diagnoses not necessarily to elicit agreement and understanding, but to have an indication of the patient's perspective prior to progressing to treatment discussions. The fact that people with dementia will have impaired processing means that minimal tokens such as

“mm” or nodding cannot necessarily be understood as acknowledgement, and therefore it may be that doctors are compensating for this by encouraging extended responses. For the majority of patients this is successful, with over 70% of patients responding more than minimally to the diagnosis. However, when it comes to managing responses before shifting to treatment discussions, doctors are using similar tactics as found in other diagnostic settings – optimistic and positive framing of the diagnosis. The difficult balance between ensuring understanding and instilling hope has been identified in other diagnostic settings. However, the nature of dementia means that optimistic communication of diagnostic information may have implications beyond that of other diagnoses, with impaired comprehension leading to further misunderstandings.

**Chapter Seven:  
“How do they want to know?”  
Doctor Perspectives on Delivering  
Dementia Diagnoses**

A 2013 systematic review on stakeholder perspectives of disclosing dementia diagnoses found that it is repeatedly reported that while doctors see the benefit of telling a person they have dementia, the stigma of the condition and lack of beneficial treatment can provide a barrier for doing so (Werner et al., 2013). Many professionals report practices of “*veiling the information*” (page e79): often not naming the illness at all and avoiding prognosis discussions. However, most of the papers exploring the viewpoints of medical professionals on disclosure were published between 2004 and 2008. As previously discussed, there has been a dramatic shift in the policy and culture of dementia diagnosis, with an emphasis on increasing diagnosis rates in the early stages of the condition in order to maximise access to treatment and support. There have been few studies that have examined the effect that these changes have had on how professionals view dementia diagnosis delivery (Dubois et al., 2015). One study interviewed GPs in the UK and found that they viewed the drive to increase diagnosis rates more positively, and accepted their role as important in this drive, since the 2009 National Dementia Strategy (National Audit Office, 2010). However, the research with professionals working in secondary care memory clinics is scarce.

What is the relationship between the views of professionals’ about their communication elicited in focus groups and findings from applying conversation analysis (CA) to their communication with patients? It has been claimed that CA dismisses the effects of the social context of the interaction on how the interaction unfolds: analysts regard all that is relevant to the interaction as that which is visible within the interaction, and there is thus nothing that knowledge of the broader context can add to the analysis. However, this is a misunderstanding stemming from Garfinkel’s rejection (as developed by Sacks and Schegloff) of context as a ‘bucket’ that contains and thus explains the actions of speakers (Heritage and Atkinson, 1984). The CA viewpoint is that utterances *are* shaped by context – which includes the larger environmental context as well as the local context within the sequence – but that utterances also *shape* the context for the next utterance, and thus context can change at any point in the interaction. Therefore, when conducting CA, the context that comes from the environment that the speakers are in and the positions they hold in that environment should not be completely ignored, but analysts must be

aware that the ever-changing nature of context means that these factors cannot be “*determined in advance and independent of the participants’ own activities*” (Heritage and Drew, 1992, :21).

Therefore, the inclusion of the findings from focus groups in the thesis alongside the CA analysis will not change the results of the previous chapters or attempt to explain why the doctors deliver dementia diagnoses as they do. Instead, given the aforementioned changes to dementia awareness and policy that has occurred in recent years, and the differing nature of dementia compared to other diagnoses that have been extensively studied in CA, the doctor perspective on diagnosis delivery will be an interesting supplement to the findings discussed in the previous chapters.

The aim of the focus groups was thus to explore the views of doctors taking part in the study about communicating a diagnosis of dementia within the memory clinic structure in the UK.

## **Methodology**

Four focus groups were held between February and April 2015 with the clinicians who were taking part in the ShareD study. Two focus groups were held in Devon Partnership NHS Trust (with differing participants), one with the doctors working in Camden and Islington NHS Foundation Trust, and one with doctors working in East London and Barts Health NHS trusts.

The focus groups were held in rooms in NHS buildings close to where the clinicians worked. They were audio and video recorded, and only the facilitators and participants were present. There were 3-6 clinicians per group, and the groups were approximately 90 minutes long.

The aim of the focus groups was to elicit doctor thoughts and feelings about communicating with patients in diagnosis feedback meetings in memory clinics. As recommended by Kreuger and Casey (2001), a topic guide was used to ensure the focus groups followed a structure that was designed to elicit the information to this end (see Appendix F). Following the guidelines set by



Kreuger and Casey, the topic guide was developed in a group of meetings with the ShareD team focussing on issues identified in the systematic review (Chapter Two) (Dooley et al., 2015) and study aims. The topic guide was reviewed by the Alzheimer's Society Research Network to ensure clarity.

The focus groups were conducted in a "structured eavesdropping" style, where doctors were encouraged to talk among themselves about their beliefs about the topics raised by the facilitator (Kitzinger, 1995). This example from one of the transcripts illustrated how this unfolded:

*Facilitator: Is (prognosis) part of what you talk about?*

*Doctor 1: I do a little bit if I'm talking about donepezil because I'm a big, I'm a big prescriber. And I sort of believe, you know, in the drugs.*

*Doctor 2: Oh dear!*

*Doctor 3: I'm glad you bring that up*

*Doctor 1: You want people to try the donepezil if they can, and so part of the way I'll introduce that is to talk about trajectories. You know if things have been going downhill, then perhaps the leveler.*

*Doctor 3: The leveling off. Yes, that's what I do. I've got a leveling off thing that I do. And the other time that I do is with lasting power of attorney.*

Therefore, the topic guide primarily ensured the focus group discussions held a structure surrounding the topics of communication in memory clinics, but group interaction and discussion surrounding these topics was encouraged. The resulting data therefore reflects the individual and shared perspectives that resulted from these discussions.

### Participants

The doctors were all recruited through their involvement in the research project. All except one (H78) are the doctors who are in the video recordings analysed in Chapters 4-6. There were 13 old age psychiatrists and 2 geriatricians. Participant characteristics can be found in Table 14.

**Table 14: Characteristics of doctors in focus groups**

<b>Doctor Characteristics</b>	
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

The focus groups were conducted as part of the ShareD study. The questions were therefore aimed to elicit the doctor perspectives broadly on communication in diagnosis feedback meetings in memory clinics, including both the diagnosis delivery and how to include patients in management decisions. The analysis was conducted with these ShareD research questions in mind and thus captured the entire content of the recorded discussions.

The focus groups were transcribed and analysed between November 2015 and July 2016. The analysis was planned and conducted collectively by a clinical researcher (CB), my supervisor (RM), and myself over a total of 27 analytic meetings, ranging from 90 minutes to 4 hours in length. NVivo 11 and Microsoft Excel were used to generate codes, categories, subthemes, and themes. A thematic analysis methodology was followed, using the 6 phases described by Braun and Clarke (Braun and Clarke, 2006).

#### *Phase 1: Familiarising yourself with the data:*

CB and I transcribed half the focus groups each. We all watched the video recorded focus groups and read all the transcripts to familiarise ourselves with the data and ensure the transcripts accurately reflected the recordings.

### *Phase 2: Generating initial codes:*

The transcripts were divided into units consisting of one line of text. An inductive approach was taken, with each line given equal attention and a code applied. These initial codes were descriptive rather than interpretive, but were not simple repetition of the words used by the doctors themselves. Instead, these codes aimed to ascribe a “*unit of meaning*” to each line (Miles and Huberman, 1994, p56), with multiple codes sometimes used for one line of text. This line-by-line coding took place over 9 group analytic meetings, with CB leading on the analysis in between meetings. Nineteen per cent of the data was coded line-by-line as a group. The group meetings were also used as an opportunity to reflect on the coding that had been done by CB between meetings, for example changing the wording to avoid adding meaning to the text that was not in the data and ensuring the context of each line was taken into account.

### *Phase 3: Searching for Themes:*

The next stage of the analysis involved grouping the line-by-line codes into categories. There were 599 line-by-line codes at the start of this stage. Seven analytic group meetings focused on moving from codes to categories. Codes were grouped into categories according to similarities. Similarities within and differences between categories were examined repeatedly (Patton, 1990). This resulted in 39 categories.

The COREQ guidelines state “*specifying the use of multiple coders or other methods of researcher triangulation can indicate a broader and more complex understanding of the phenomenon*” (Tong et al., 2007). Inter-rater reliability therefore was calculated at this stage in order to sharpen the definition of the categories and ensure coherence and replicability of the analysis (Miles and Huberman, 1994, Frith and Gleeson, 2004). I double coded one of the focus groups that have been coded by CB, which consisted of 35% of the data. Cohen’s kappa produced a score of 0.88 indicating high agreement.

### *Phase 4: Reviewing the Themes*

The development of the 39 categories into 18 subthemes and 8 themes took place over 7 analytic group meetings. Firstly, groups of categories were identified and repeatedly examined by looking similarities and differences in their underlying meaning, often referring back to the original codes and transcripts to ensure homogeneity within and heterogeneity between groups. For example, doctors spoke of trying to provide personalised care for patients before, within, and after the diagnosis feedback meeting. These categories were therefore grouped according to the underlying issue raised by both: “Service and personal strategies for maximising continuity within the memory clinic structure”. Some categories were sufficiently different from others to remain as their own subtheme.

Subthemes were further grouped into overarching themes using a process of “*subsuming particulars to the general*” (Miles and Huberman, 1994, p250). The aim in this process was to generate higher level groupings of the issues identified by doctors in different aspects of the diagnostic communication, and thus the grouping followed these principles. For example, doctors had spoken about breaking bad news in the context of training and support, practicalities in terms of evaluating patient readiness for news, and their strategies for delivering bad news. That these subthemes all related to bad news deliveries meant that they were grouped into an overarching theme according to the issue raised: “*Breaking bad news: application and suitability of existing frameworks and training*”.

#### *Phase 5: Defining and Naming the Themes*

The final grouping themes were developed and named over 4 meetings. The naming of themes involved identifying issues that tied the relevant subthemes together and capturing the common phenomena pertaining to the these subthemes.

#### *Phase 6: Producing the Report*

As stated above, the analysis of the focus groups was conducted as part of the ShareD study, aiming to elicit doctor perspective on all aspects of communication in memory clinics, not just the communication of the dementia

diagnosis. This has been written up as a paper and submitted to Ageing and Mental Health for publication.

The data presented in this chapter has been selected from the overall findings in order to retain the focus on diagnostic communication in the previous chapters. Therefore the theme “Shared decision making: capacity, cognitive impairment and companion involvement” will not be included in the results, due to its focus on communication around decisions on management of dementia. Additionally, the theme “Playing to two audiences” will not be included, as much of this theme includes the pre-existing beliefs of the companion surrounding the patient’s symptoms and treatment needs. While the challenge of communicating to patients when companions are also present is highly relevant to the communication in memory clinics, this has not been explored in the analysis of the diagnosis delivery and thus will not be presented here in order to maintain on-going focus. Additionally, the individual categories “MCI: an uncertain diagnostic entity with variable follow up” and “Assessing cognition in BME patients who have different explanatory models” will not be discussed here, as they are not focused on the analytic issues explored in Chapters 4-6.

### Findings from the Doctor Focus Groups

The 39 categories, which were organised into 18 subthemes and 8 overarching themes are summarised in Table 15. The 6 themes most relevant to the analysis of the diagnosis delivery will be discussed (highlighted in bold in the table).

**Table 15: Themes, subthemes, and categories**

<b>Theme</b>	<b>Subtheme</b>	<b>Category</b>
<b>Public awareness and political agenda: service and individual responses</b>	Media portrayals, stigma, and dementia as the political agenda	Dementia diagnosis as a political agenda in the face of inadequate funding and follow up
		Decreasing stigma, comparisons to cancer, and increasing media portrayals of dementia
	The evolving remit of memory services: managing increasing referrals	Local variations, quality improvement, and ways of adjusting to increasing referrals
		Evolving remit of memory clinic: dementia assessment or ageless

		catchall?
<b>Making and delivering a diagnosis: challenges, strategies and utility</b>	Making and accurate diagnosis with limited time and information	MCI: an uncertain diagnostic entity with variable follow up
		Assessing cognition in Black and Minority Ethnic (BME) patients who have different explanatory models
		Limited time: inherent diagnostic challenges and being 'parachuted in'
	The utility of a dementia diagnosis	Value of dementia diagnosis: understanding symptoms, accessing services
Playing to two audiences	Doctors' shifting alliances: Balancing patient and companion needs and involvement	Attending to differing needs and contributions of each party in triadic consultations
		Triggers for patient marginalisation, and strategies for inclusion
		Identifying and managing carer burden
	Triadic dynamics: old patterns, new stresses	Role of companions in the consultation: from advocacy to protective caregiving to infantilisation
		Longstanding relationship dynamics and new stresses emerging in feedback appointments
	The complex, shifting role of companions: insight, expectations and attributions	The impact of the diagnosis on companions: realisation and distress
Companions' attributions and (mis)understanding of symptoms		
<b>Breaking bad news: application and suitability of existing frameworks and training</b>	Limited training and support for the complex and emotional task	Breaking bad news training: applications and deviations from existing frameworks in delivering dementia diagnoses
		The emotional impact on clinicians: the 'litany' of patients and lack of supervision
	Context and preparation: assessing patient insight and readiness for the diagnosis	How patient readiness, insight, and context influences the delivery
		Differing perspectives on asking if patients want to know their diagnosis
		Role and availability of pre-diagnostic counseling
	The process of diagnosis delivery: considered use of labels, building personalised narratives	The spectrum and personalisation of language: tailored use of D and A words and 'labels'
		Communicating non-dementia diagnoses and the managing of the associated stigma

		Aligning the evidence to patient narrative
		Challenges in explaining dementia and its subtypes
<b>The range of insight, engagement and emotional reactions to diagnosis</b>	The spectrum of insight and interest in the diagnosis	The spectrum of insight and interest in the diagnosis: from fear and help-seeking to anosognosia and denial
	Varying emotional responses to the diagnosis and its practical implications	The range of emotional responses to diagnosis and relationship with insight
		Emotional responses to driving discussions: the first concrete marker of loss of independence
<b>Balancing honesty, hope, and uncertainty</b>	Instilling hope: the message of living well and the uncertain efficacy of medication	The multifaceted role of medication: uncertain pharmacological efficacy, and a tool for moderating bad news
		Offering hope and softening the blow of the diagnosis
	Communicating practical implications and prognostic uncertainties	Approaching driving discussions: a tangible consequence, and loss of independence
		The challenges of communicating prognosis
Shared decision making: capacity, cognitive impairment and companion involvement	Shared decision making: triadic communication within the context of pre-existing relationships	Communicating and making decisions with patients who have partial capacity
		Approaches to medication decisions: managing expectations and the importance of practicalities and context
	Information provision and cognitive impairment	Giving information: general principles and specific adjustments for patients with cognitive impairment
<b>Providing continuity of personalised care within service constraints</b>	Service and personal strategies for maximising continuity within the memory clinic structure	Flexibility within memory clinic pathways: attempts to provide continuity of care
		The role of 3 <sup>rd</sup> sector organisations in providing post-diagnostic follow up
		The variable availability of post-diagnostic counseling and impact on what can be left for another day
		“Going in cold”: meeting for the first time in feedback, and ways of getting a sense of the patient
	Balancing personalisation and flexibility with institutional agendas	Balancing institutional, patient, and companion agendas in diagnostic feedback

## Public awareness and the political agenda

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

Doctors discussed increased public awareness of dementia and the differing effects of this on their practice in the memory clinic.

*“I think we’re in the middle of a fairly rapid cultural change at the moment. Dementia is on the news every day now isn’t it?.. So more people say “have I got dementia?” than maybe a few years ago.” H51*

The increase in awareness was reported to be evident in people’s concerns and expectations when attending diagnosis feedback, which could lead to misconceptions about the prevalence or treatment of dementia.

*“There’s this huge misconception, certainly I have this struggle with my parents all the time, which is that people think, I think the public thinks that everybody gets dementia.. And no matter how much I tell my mum and dad that you know ‘only one in five people over 80 have dementia’ they still think that.” H40*

*“Because people come in and say ‘I want this tablet so I can stop this’. Because every week in The Mail or The Express there’s an ‘X’ that cures dementia.” H50*

Doctors still felt that increased dementia awareness was a positive development, particularly in the reduction of the stigma associated with the condition. This was compared to how the stigma surrounding cancer has changed.

*“There is a need to de-stigmatise the word, such as, you know people didn’t talk about cancer. You know, cancer was potentially a catching word, you know, if you, it’s a taboo. And so part of me feels, rightly or wrongly, is that using (the word ‘dementia’) normalises it.” H17*

The doctors felt that the focus on diagnosis rates in the political agenda was causing difficulties in the gap between increasing referrals and provision of post-diagnostic support.



*“It’s a big political issue at the moment. ‘Dementia’ – it’s kind of a named illness in various policies and blahdeblah. And all kinds of ill thought out dementia screening initiatives, so lots of talk of increasing diagnostic rates and coding and registers, but no talk of psychosocial intervention, and no talk about the sort of predations on all budgets and social services delivering the very things that we know will help these people.” H17*

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

There was an agreement that changes in policy were putting increasing pressure on doctors to make dementia diagnoses, and this caused some concern as to whether the diagnoses delivered were always accurate.

*“Because with the clinic – it’s a diagnostic clinic. It’s an issue of, you know ‘if you’ve got a hammer everything looks like a nail’ kind of situation going on. That we’re there to diagnose dementia not depression or anxiety or marital problems. So you often...you know, diagnose dementia! So you know I think that’s always a bit of a worry.” H40*

*“Either your diagnostic accuracy goes down or the delays increase, people wait 12 months to get a diagnosis. It is balancing.” H43*

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

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

Doctors described how they decide if a person has a diagnosis of dementia; bringing together all the information collected in the referral letter and initial assessment meeting. They reported uncertainty in making diagnoses.

*“It is very much a balance of probabilities isn’t it – the age, the GP referral, the CT scan, the cognitive testing, the informant, the patient history and then the clinical history.” H51*

*“You know we spend half our life guessing on incomplete information. That total uncertainty.” H49*

The fact that in the majority of memory clinics doctors were not collecting the information themselves meant that they could face some difficulties if other clinicians had not provided the information needed to make the diagnosis.

*“You’re at the mercy of the person who’s taken the collateral history, all the history, and for us depending on which day that can be variable at how skilled the person is at probing and sort of getting to the bottom of things.” H40*

*“You’re also at the mercy of the GP letter, the GP having done the blood tests and them being there, which they’re often not. And the radiologist having reported on the scan, which they haven’t. So the whole thing can feel quite vulnerable.” H41*

Some of the information gathered was deemed more important than others for making a dementia diagnosis.

*“Yeah, because I reckon you can probably make a diagnosis of dementia without the scan if you had to, and without an ACE (cognitive test), but you couldn’t possibly make it without the history.” H49*

The importance of the patient’s history in making a diagnosis meant that doctors experienced more uncertainty when they had not met the patient prior to diagnosis feedback, and most had not met the patient prior to this point. They explained their strategies for engaging patients in discussion prior to delivery to determine the accuracy of their diagnosis.

*“So sometimes I am doing more information gathering or reviewing mental state maybe. Just to get a bit more of a sense of the person who I often haven’t met before.” H17*

*“And how they walk in the room, and how quickly they, their speech flows and I think you learn so much from just seeing people briefly.” H49*

While doctors did demonstrate that they had adjusted to the difficulties surrounding diagnostic accuracy, it was still a cause for concern.

*“It’s bringing that all together in the short time that we have. I don’t know if I’m getting better at it, but it’s, it causes me anxiety sometimes.” H51*

### *The utility of a dementia diagnosis*

The doctors felt that one of the primary reasons for diagnosing dementia was to provide patients and their companions with a label that would help them access additional support services that would benefit them.

*“I know that in (place) we have a fairly good range of services, both for people with mild symptoms and more severe. So that makes me feel that, you know, it has worth. It’s not just a medical labelling.” H17*

*“You know from the organisational point, we need to give a diagnosis with its name.” H02*

The other function of the diagnosis identified by doctors was for the patient’s family: to give them license to use the ‘dementia’ label and aid them in making future plans.

*“I’m definitely aware of that by using the word and saying the diagnosis, saying dementia, saying Alzheimer’s, and giving them a leaflet you’re giving the carer permission to keep going down that road with them.” H40*

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

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

The majority of doctors had not received training on how to tell people they have dementia.

*“I don’t think I’ve had formal training, apart from the sort of thing (name) was alluding to of training in medical school around ‘breaking bad news’ as it would be called. In my mind I remember being filmed in medical school and doing it and it being about telling an actor, an actor playing the role of a wife, that her husband had died. So you know, it’s a very different kind of scenario to giving a diagnosis of dementia to someone.” H22*

Other doctors did apply aspects of their training they had received to diagnosis delivery in memory clinics.

*“He (the trainer) got us to think about how you can ask permission and how you can, how much people would like to know, and at what point they would like to stop and to give them the ownership of feeling in control of that conversation.” H41*

The psychological impact of the task of telling people they have dementia on the doctors was also discussed.

*“And you know, the point is that there is a lot of pain and angst, you know, how do we deal with, you know, the litany of the patients that have to be told, the numbers of patients that have to be told that they’ve got an incurable illness?” H07*

*“I’m just parachuted in at the end to tell them and I just think that’s awful.” H50*

There was no official support for doctors to discuss cases that troubled them, but many doctors described the advantages of working in the diagnostic feedback clinic with other clinicians as peer supervision.

*“We gave the diagnosis with the team psychologist. Which helped throughout the session, and after that, we just had you know, 10 minutes basically: ‘Alright?’ ‘Okay?’ Yeah, and then we revisited it over the next few days because it was very difficult.” H02*

*Context and preparation: assessing patient insight and readiness for diagnosis*  
Doctors discussed the wide range of patient readiness (or lack of readiness) for the diagnosis.

*“Some people will walk through the door and say just, just tell me, I know what’s happening. And there are other people who sort of come in, not expecting it at all and you obviously have to change your approach.” H78*

Establishing the person's orientation and insight into the diagnostic feedback meeting at an early stage was necessary.

*"You can't deal with your so-called medical agenda until you can tell the patient's agenda. And establishing that they're there in order to receive the diagnosis is paramount really. Because if they don't know that's what they're there for then you know, you haven't even got to first base."* H07

The doctors reported aiming to build a narrative based on the perspective of the person with dementia, and leading them to a place where they will accept the diagnosis.

*"I think I'm partly trying to find out what it is that they think. Not so much what they know, but what they think, so that I can subtly bring them around to my point of view as to what might be wrong with them."* H21

*"Often, you're coming to this meeting with very different thoughts, very different, I guess, ideas, to exactly what they're expecting. So it's helpful to find something that you can agree on, some sort of symptom which you can then begin to build a kind of story around really."* H22

Discussion of patient awareness of the diagnostic process incorporated the issue of patient consent to deliver the diagnosis. Some doctors felt that if patients had been through the referral and assessment, they have already consented to the diagnosis. Others reported incidents where the possibility of receiving a diagnosis had not been discussed with patients.

*"You know they get a letter saying 'come to see the doctor again for feedback about diagnosis'. So I think, well that's what they came for."* H21

*"I'll give you a story of a woman who, the daughter went to the doctor and said 'I think my mum's got dementia'. Doctor referred her without seeing her. The daughter intercepted the clinic letter and didn't show her, and said 'Mum we're just going for a coffee, do you want to come?' and brought her along to memory clinic."* H50

As discussed in Chapter 5 many doctors asked patients if they wanted to know the diagnosis in the diagnosis feedback meeting. Doctors reported service-driven reasons for asking this question, as well as some concern as to what to do if people say they do not want to know.

*“I think on the back of MSNAP, Memory Service National Accreditation Programme, or whatever it’s called, that writes varying standards, it has ones about asking about diagnosis and what you want to know. And that’s made us be more explicit about asking those questions.” H17*

*“Since I’ve started doing the clinic and there’s that totally awful letter that (name) knows I hate, which I believed, clearly wrongly, that we were sort of bound to use, and it says ‘after ascertaining that they wish to know the diagnosis..’, so I’ve started doing that now..” H49*

*“I think I find it very hard to know how to say ‘there’s something..’ ‘how much do you want to know?’ And even if you don’t want to know that, maybe you do actually want to know what we can do to help, in which case we’re talking about Donepezil (cholinesterase inhibitor) and memory groups. Yeah, I find that, that whole concept quite difficult.” H22*

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

The doctors placed great importance on delivering the diagnosis appropriately to the patient as an individual, so adjusting the information provided as to the patient’s needs. However, this could be made difficult by the fact they often had never met the patient before.

*“It’s very difficult though, I actually really hate going in cold and theoretically giving a diagnosis. If I’m going to give someone a diagnosis of Alzheimer’s I would normally spend the first half hour of the assessment, and perhaps in psychiatry we’ve got more time, but I would normally spend that first half hour getting the information, but also working out who’s in front of me. You now how do they want to know? .. How do they want me to say it?” H49*

The initial stages of the meeting – discussion of patient symptoms and feeding back the test results – were described as important in determining how doctors approached the diagnosis itself.

*“There’s a narrative: they come for the dementia, so there’s a problem here and let’s talk about it and talk around that. Maybe the score, the history or whatever it is. Get more of their narrative, more of what they’re about, what’s going on and then run with that. They usually like to see the scan. Get the scan up and they’re – “oh my brain!” Most people really like that.”* H51

*“I might say to them you’ve come here, you saw another doctor, or me at home, and you had some investigations and you’ve come here to think about, to get the results and to find out what it means. Say like ‘you’ve had a scan do you remember?’ Some people don’t and say no I didn’t have it. And yeah, then ‘would you like me to tell you what it said?’ and so, I would offer them the opportunity to have that information if they want to.”* H21

Doctors reported variation in how patients responded to cognitive test feedback, with some patients realising the extent of their difficulties when they struggle with certain questions, and others misunderstanding their scores on feedback.

*“They get into the tests and they think, ‘there are simple things like drawing a clock face and I couldn’t do it’. They often say ‘it’s simple, there’s a clock on the wall, but I couldn’t do it’. And that leads into, ‘well that isn’t quite right’”* H50

*“If you compared (the cognitive test results) with any other sort of scoring system, you know, getting 50% is a pass isn’t it? Whereas we’d be pretty alarmed.”* H49

When it comes to delivering the diagnosis, doctors showed awareness both of the importance and the potential impact of naming dementia as the patient’s diagnosis.

*“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.” H07*

*“Often it’s the first time anyone has mentioned the word dementia to them. Because the GP says ‘oh well we’ll just go off and test your memory’.” H43*

They discussed giving particular attention to the placement of the diagnostic labels ‘Dementia’ and ‘Alzheimer’s disease’.

*“It’s a little dance isn’t it? Using the appropriate language at the time, that’s how it is.” H51*

*“I always say that people have been invited because we want to look at their memory to try and work out whether they’ve got a dementia or something else. And then I come back to that later. So I suppose the word’s been put out there.” H49*

*“I start off euphemistically saying ‘so we should start thinking about what we can do to protect your memory at this stage’ and then I might talk about the kinds of drugs that people use for things like Alzheimer’s disease. ‘And those are the sorts of drugs we might use for you because I think you might have Alzheimer’s’. So I go that slightly.. circuitous route.” H40*

One doctor reported not using ‘dementia’ terms when he felt that it would not be beneficial for the patient, for example if they were in later stages of dementia.

*“Rather than saying you’ve got Alzheimer’s disease and this is the medication, and this is the dementia care team, sometimes I’ll say you’ve got a memory problem, there’s medication for it, let’s discuss the medication.” H43*

It was pointed out that even the names of the clinics did not mention dementia.

*“I guess it’s sort of sugaring the pill isn’t it? That they’re called memory services. It’s euphemism.” H17*



Doctors debated the importance of naming 'dementia' when telling patients their diagnosis, and there was differing opinion on the importance of providing the diagnostic label.

*"And does it really matter, whether we use the word dementia?.. Most of the time I just say you've got a memory problem and we call it dementia or whatever but it's just a memory problem and this is the treatment for it. And patients are often happy with that."* H01

*"At least then you feel you've got it out there and they can talk about it. Because they've heard it from you and it's there, it's not anything that's worth treading around."* H41

Doctors reported that there could be confusion regarding the difference between Alzheimer's disease and dementia, which caused difficulty in delivering diagnoses.

*"Another common things is, 'Oh I've got dementia, not Alzheimer's, I'm happy with that.'" H01*

*"If you mention dementia and Alzheimer's then you get into this sort of long convoluted, trying to explain the difference between the two, which is actually quite tricky anyway."* H03

Many doctors aimed to differentiate the early stage of dementia that most of the patients they saw were in, from the later stages of dementia that the patients and their families associated with the condition. They reported following the diagnosis delivery with discussion of the helpful aspects of receiving a diagnosis.

*"I would normally say "it's a dementia", and then stop there and have a discussion.. Because often people have completely the wrong idea of what dementia is, and you know that's the opportunity to think, oh yes, Auntie Nan had that she's in a care home she can't speak at all or something and then you can challenge some of the ideas about that."* H17

*“And I say that it helps other people to understand what it is you’re finding difficult and to make plans to help you to deal with it, so it’s seen as a positive thing because it helps people to identify ways of helping you. So I think there’s lots of ways you can package the same stuff a lot more positively.” H41*

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

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

As discussed above people can present to the memory clinic with varying levels of insight. Doctors reported that lack of insight continues to affect how patients respond to the dementia diagnosis once it is delivered.

*“I never quite know what to do when you’ve said it all, and then as they’re going they say ‘well it’s OK because there’s nothing wrong with me’” H49*

Doctors shared strategies of adjusting their approach with patients who do not appear to register the diagnosis, often discussing treatment and planning primarily with the patient’s companions.

*“That’s something that would be a good sort of guideline to really emphasise to the carer that the person with dementia will probably not remember this. You’re acting as their memory. They don’t, they will not, remember this.” H21*

Doctors discussed whether making people understand they were receiving a diagnosis of dementia and that they needed support was necessary. It was agreed it varied on a case-by-case basis.

*“Because they are lacking in insight they’re refusing help or they’re putting themselves at risk at home then that’s something I really worry about. Whereas if they’re lacking insight and they’re refusing the Donepezil (cholinesterase inhibitor) that I’m offering then I feel that that’s a less of a make or break kind of decision.” H22*

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

Doctors connected lack of insight with a lack of emotional response to the diagnosis.

*“Don’t you find the ones with very little insight who are sitting there blithely unconcerned about anything, don’t seem to be concerned with the diagnosis either? You say that to them and it’s all sort of water off a duck’s back, isn’t it?” H41*

Doctors described strategies towards dealing with resistance (or “hostility” (H78)), such as seeing the person again in their own home. Strong emotional responses were reported as rare, but doctors reported that they occur more often at later stages in the meeting when practical repercussions of the diagnosis are discussed. This is particularly the case when doctors tell patients they may have to stop driving.

*“Someone’s got some insight that you are making a diagnosis and you tell them that they need to inform the DVLA (Driving and Vehicle Licensing Authority). That’s gone very badly wrong sometimes.. They don’t seem to be aware of it as a possible consequence.” H40*

*“I think 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. So I think that can be more difficult than the diagnosis because that they can’t remember, but if they can’t drive they can’t drive.” H21*

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

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

The conflicting goals of being honest but hopeful, while also communicating the uncertainty of the prognosis of dementia, were discussed by the doctors.

*“I think my concern around that has always been around striking the right balance, not scaring people too much, but not not saying it and not creating misunderstanding” H78*

*“I want them to understand, but not to understand too much. Because I think, you’ve got to have on board that this is an extraordinarily difficult way to go down, and to know that you’ve got an illness, and 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.” H21*

A message of “*living well*” (H40) with dementia was deemed important by doctors to help patients cope with their diagnosis.

*“There’s something about not letting the diagnosis swamp them, you know, that they’re still the same person tomorrow, with a bit more baggage sort of thing and that you can, as you say take control of it, make decisions, continue going on your cruise, you know. But just perhaps with a slightly different support system around you.” H49*

Many of the doctors felt ambivalent as to the efficacy of the cholinesterase inhibitor medication for dementia, and there was some discussion as how to communicate that to patients. However, many doctors reported using the offer of treatment as a method of instilling hope after diagnosis.

*“And I think, from the moment one starts talking about the potential, the treatment, I think it already has a placebo effect on the actual adjustment or the sort of stress reaction of the patient. Okay, ‘ah there’s something, there is a tablet to start with.’” H02*

### *Communicating practical implications and prognostic uncertainties*

Doctors find the uncertainty of the prognosis of dementia difficult to communicate to patients.

*“You know some of the people will go very, very slowly and there’ll be very little change over years and other people will catastrophically drop. So I think there’s less specific medical stuff to do, which is harder for us doctors. And it’s harder for people to manage.” H21*

Doctors reported addressing prognosis differently with different patients, depending on how much they want to know and at what stage their dementia is.

*“I think it’s variable depending on who you’re talking to really – what level they’re at. If somebody really, really wants to know, I will do my best and I will say, things have changed for you quite a lot in the last 2 years... It’s quite possible that it may progress, you know, along a similar course for the next 2 years.” H41*

*“A lot of the patients that we see in (place) are at quite an advanced stage... so you say that you’ve got a memory problem, there’s medication for it, (and) it may get worse, rather than saying it will get worse.” H01*

Doctors reported often skirting around the practical implications of dementia and its prognosis, aiming to avoid emotional trauma.

*“So things that might happen in the future and might have to be thought about. In terms of living arrangements, it’s-, you don’t want to scare people and it’s already a lot to take in I think. You’re already quite busy telling them just the basics and I think it’s judging what people are worried about and often people will ask you about kind of specific things that they’re concerned about kind of looking to the future of that diagnosis and the implications of it.” H78*

### Providing continuity of personalised care within service constraints

#### *Personalisation and flexibility within the institutional agenda*

Doctors were aware of following a specific medical agenda with patients; there were certain topics – medication, lasting power of attorney, driving – that needed to be covered in the feedback meeting. However, end of life planning (or ‘advance care planning’), despite being recommended by the NICE guidelines to be discussed as early as possible, was deemed an unsuitable topic within the diagnosis feedback meeting.

*“It is just so not appropriate to talk about advanced care planning at the point at which you tell somebody you’ve got dementia. I mean it’s like, you know, and I’ll just kick your head in as well while you do it. It just feels so, just, poisonous.” H07*

### *Service and personal strategies for continuity*

Regarding the patient's understanding of the diagnosis, and enabling them to make decisions about their future, the doctors felt strongly that the diagnosis was a journey – and that the feedback was just the start.

*"I always think I, that dementia diagnosis is a process. And that more questions arise as the implications sinks in." H51*

Doctors felt a pressure of service constraints on what they can offer at the feedback meeting, particularly in relation to the time they had with the patient.

*"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." H17*

For this reason, post-diagnostic follow up was seen as extremely important in ensuring that the needs of people with dementia and their families were met.

*"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." H07*

Many doctors felt concern that they would not usually see the patient themselves after the diagnostic feedback meeting. There was variation between memory clinics as to whether nurses within the clinic ran post-diagnosis meetings or whether there was third sector involvement, such as support workers from the Alzheimer's Society. Doctors felt that if there was some continuity in the staff between feedback and post-diagnosis then it was better for patients.

*"I'm always really pleased when I spot one of my GP surgeries (in the patient's notes), because then I know that my team will be doing the post diagnosis session... And also I feel more confident. So I can say to them 'look if anything goes wrong just ring us' because I know that actually it will be me" H49*

*“I mean for me the session is successful when I have the chance to eventually introduce the person from the Alzheimer’s Society. Let me introduce you to my colleague, we have these people who will be sort of following you through the process.” H02*

## **Discussion**

Analysis of focus groups with psychiatrists and geriatricians delivering dementia diagnoses resulted in 8 themes, 6 of which were discussed in this chapter. These outlined the key challenges for doctors in delivering dementia diagnoses: responses to public awareness and political agenda; the challenges, strategies and utility in making a diagnosis; training and frameworks for breaking bad news; the range of insight, engagement and emotional reactions of patients; balancing hope, honesty and uncertainty; and providing continuity of personalised care.

The 6 themes that have been presented in this chapter will now be reflected upon according to two underlying threads within the focus group discussions. The first of these is doctors’ beliefs about the purpose and utility of a dementia diagnosis. The second is the external pressures and constraints of services beyond doctors’ control.

### **Beliefs about the purpose and utility of dementia diagnosis**

As found in the literature, doctors reported a change in perspectives on dementia diagnostic disclosure in the last 10-20 years along similar lines to cancer (Dubois et al., 2015, Werner et al., 2013). While studies at the beginning of the decade were showing clinician reluctance in and avoidance of telling patients they have dementia (Bamford et al., 2004, Monaghan and Begley, 2004), the doctors in this study reported consistently telling people their diagnosis. However, their beliefs about what a dementia diagnosis represented and the purpose of the diagnosis for the patient was apparent in how they talked about approaching the diagnosis delivery.

While doctors spoke positively about removing the stigma of dementia and made comparisons to cancer in its rising prevalence in public discussion, there was clear doctor anxiety in causing upset to the patient and their companion when delivering the diagnosis. This reflects studies of stakeholder opinions of dementia diagnosis disclosure, where a central concern is the negative emotional effect on the patient (van den Dungen et al., 2014, Carpenter and Dave, 2004, Milby et al., 2015). The increase in awareness of dementia and the effect of the media on treatment expectations caused added concern for doctors about how to 'let down' those who attended the memory clinic hoping for a drastic improvement. There was much discussion about the strategies to approach the dementia diagnosis, including building a narrative, using the test results, and the "little dance" in the placement of the term once the patient was ready. These strategies reflect the behaviours described in the previous chapters, and in other settings (Turowetz, 2015). However, what this demonstrates is that while there may have been a change in beliefs about the importance of using the 'dementia' label and telling people their diagnosis, doctors are very attuned to the delicacy and challenges involved in imparting this news. The current doctors were telling people their diagnosis, as evidenced in the video recordings, which shows a development from the avoidance of the dementia label reported in previous studies (Robinson et al., 2015, Peel, 2015). However, there remains a prominent awareness of the stigma and impact of dementia, and resulting discomfort for doctors in delivering the diagnosis.

The doctors' perspectives correspond with studies of patient and companion responses to dementia diagnosis. Stokes et al (2015) describe patients and companions seeing the benefit of having a diagnosis in their personal understanding and management of the condition, which is at odds with their wider, more stigmatised perceptions of dementia within society. Patients and companions will have different reactions to dementia diagnoses – from positive coping responses, to denial, to grief (Aminzadeh et al., 2007). The doctors' heightened awareness of the latter two responses and wish to encourage the first was evident in the description of their approaches to naming the diagnosis, and thus their beliefs in the purpose of communicating the diagnosis to patients.



Doctors named two main purposes of diagnosis disclosure: accessing support services and for the patient's family to understand the symptoms of dementia. They described an aim to emphasise "living well" with dementia. If doctors see these outcomes as the ultimate purpose of diagnosis, there may be an institutional agenda to speak positively and encourage patient engagement in treatment and support discussions. Doctors reported that this affects how they manage patient responses to diagnosis, which is similar to descriptions of other settings where the institutional aims will affect how responses are managed: for example while emotional responses may be sympathised with in helpline calls, they may be challenged in psychotherapy (Peräkylä and Sorjonen, 2012).

However, as also discussed in Chapter 6, one of the key issues surrounding the optimistic perspective on the dementia diagnosis is the avoidance of prognosis discussions. Doctors reported sometimes actively avoiding the specific details of how dementia will develop unless patients ask outright. They reported that one of the reasons for this was that there is little way of knowing how individual patients will progress, but a key factor was avoiding "scaring" patients. The emphasis on a positive message in diagnosis has also been reported in other settings (Maynard, 2006, Furber et al., 2013), but there is evidence that although positive messages can reduce distress in patients, they also cause people to remember diagnostic information less well (Porensky and Carpenter, 2016). Deliberately withholding this information is also paternalistic in that it removes the choice of the patient and their companion (Karnieli-Miller, 2007). Research shows that the primary complaint that relatives of people with dementia have about diagnosis is that they were not given enough information about how dementia progresses in order to plan adequately for the future (Stokes et al., 2015). There was awareness among doctors that this avoidance of prognosis in favour of a positive outlook does create misunderstandings, but that decisions surrounding the later stages of dementia were not relevant topics for when the person has just received the diagnosis. This again reflects the conflict between wanting the person to understand they have the diagnosis of dementia while avoiding articulating the degenerative nature of the condition.

While doctors spoke about importance of accessing support and for patients' families to understand the diagnosis, there was less discussion on the purpose

of the diagnosis for patients. It may be that this is related to doctor perspectives on patient expectations surrounding a dementia diagnosis. A large part of the discussion on approaches to diagnosis delivery revolved around issues of patient awareness of their symptoms. They reported widely varying expectations, from people waiting to be told they have dementia to people not knowing why they are seeing the doctor. They also reported reduced emotional reactions to diagnoses when people did not display awareness into their symptoms, and that not acknowledging symptoms resulted in patients putting themselves at risk in day-to-day functioning. Doctors felt at a loss when patients displayed a contrary view on their symptoms after the diagnosis delivery, and when this occurred they reported usually changing the focus of their communication to the companion. Previous studies have also indicated that when people with cognitive impairment appear to display a lack of understanding or agreement, doctors often talk more to their families (Schmidt et al., 2009). If doctors view the purpose of the diagnosis is to put in place management strategies, and if patients are not engaging in this once the diagnosis is delivered, it appears the main priority will be to ensure that the patient's companion is on board.

However, reports from companions state that they too can assume a lack of awareness based on their relatives reaction to the diagnosis, but that from a couple of days to a month later the patient shows an emotional reaction or display of understanding (Aminzadeh et al., 2007). It is recognised that the level of awareness a person has into their dementia symptoms will not be reliably elicited in a short clinical appointment (Clare, 2004). From the way that doctors spoke about patients "with" or "without" "insight", they appear not to take this into account. However, doctors discussed emotional reactions occurring at later, more practical discussion points such as driving, as well as management of resistance to diagnosis in meeting the person at home or with psychology input, which suggests an understanding that the diagnosis is a process that will take place over more than just the diagnostic feedback appointment. This brings us to the next underlying narrative that occurred throughout the focus group discussions, and that is the systemic constraints of the memory services.

### *External pressures and constraints of services beyond doctors' control*

The pressure of external systems affecting diagnostic communication was prevalent in the focus group discussion. Doctors reported one of the main benefits of patients going through the memory clinic and receiving a dementia diagnosis was that patients and their families would have access to appropriate support. However, that was felt to be compromised by several aspects of the memory services that the doctors perceived to be out of their control.

One of the key concerns for doctors was that they were often meeting the patient for the first time in diagnosis feedback. In the current study, 75% of the patients recorded had not met the doctor before. This increased the diagnostic uncertainty and the resulting anxiety in delivering the diagnosis, which has also been described in other studies (Milby et al., 2015). It also caused communication challenges for doctors, who highlighted the importance of delivering diagnoses that were “timely” according to the individual’s needs and expectations (Dubois et al., 2015). A “timely” diagnosis has been at the centre of the drive to increase dementia diagnoses (Dhedhi et al., 2014, Robinson et al., 2015). However, doctors appeared not to be able to rely on reports from the GP or the clinician doing the cognitive assessment as to the patient’s readiness for the diagnosis, and reported trying to gauge how the patient “wants to know” at the beginning of diagnosis feedback meetings. They also reported feeling that patients had often not even heard the word “dementia” in prior to the clinic visit, which caused them additional anxiety in being the first to use this term in diagnosis delivery. This is at odds with how dementia guidelines consider a timely diagnosis should be approached, where patients should receive pre-diagnosis counselling advising the potential outcome of the memory clinic process and decisions regarding when or how to disclose should be made accordingly (Hodge et al., 2014, Guss, 2014).

The difference between the ideal structure of memory clinics and how doctors experience the reality is also evident in what happens after the diagnosis feedback. Doctors reported being concerned that patients would not always be getting adequate post-diagnosis support. Similar to previous studies, the doctors felt comforted if patients were seeing someone within their multidisciplinary team after diagnosis (Milby et al., 2015). However, this

appeared to be something that was beyond their personal control, which was a cause of concern. These descriptions of the contrast between clear diagnostic discussions followed by unsatisfactory levels of post-diagnostic support has also been reported by patients and their companions (Van Hout et al., 2001), and is becoming increasingly recognised in the literature as a key area of improvement (Guss, 2014) .

Being “shipped in” to deliver the diagnosis with no input before or after the delivery was thus an issue of great importance to the doctors. This occurring alongside the increase in memory clinic referrals gave the doctors a sense of hopelessness. The inflexibility of the structures of dementia services have been criticised in the literature (Gladman et al., 2007), and is a cause of frustration for people with dementia and their companions (Peel and Harding, 2014).

Literature exploring doctor reactions’ to and strategies for breaking bad news to patients shows that it is a stressful part of their work, but that one of the key coping mechanisms is to be able to provide high quality practical support for patients (Shaw et al., 2013). The fact that doctors are unsure if dementia patients will be receiving support is therefore likely to add to the already difficult task of delivering a dementia diagnosis, and this was reflected in the focus groups.

Doctors reported very little dementia-specific training available for clinicians in memory clinics. While studies of breaking bad news training show mixed responses as to efficacy in improving communication, they appear to demonstrate improved perceived self-efficacy for clinicians (Alelwani and Ahmed, 2014). Even without formalised training, the opportunity for peer support for doctors is likely to help with some of the anxiety surrounding dementia diagnosis (Dosanjh et al., 2001). There was discussion among the doctors once the groups were over on their enjoyment in talking about their work. Some doctors even planned to carry on meeting as a method of continued support, which evidences that the chance for reflection and peer supervision is something that doctors in memory clinics may be missing.

### Summary and Conclusion

To summarise, the focus groups identified specific challenges experienced by doctors in delivering dementia diagnoses. The recent change in policy and service structure of memory clinics – with the emphasis on increasing diagnosis rates – has increased pressure on doctors to make diagnoses. Additionally, increased awareness of dementia in the public sphere has led to earlier presentations. These two factors can lead to some doctor anxiety as to the accuracy of their diagnoses and quality of care. While doctors felt that it was important to tell people they have dementia, some reported being careful with using the terms “dementia” and “Alzheimer’s disease”, using them strategically. Doctors reported varying levels of readiness and expectation of a possible diagnosis, and the strategies they used to gauge and deal with this challenge. Doctors talked about the importance of instilling hope in patients and their families after the diagnosis, through prescribing medication and providing positive projections of the benefits of treatment. Some doctors felt concern about the services available for people with dementia after diagnosis, and felt discomfort and a loss of control when they did not know who would be providing the post-diagnosis support.

While doctors were clearly aware of the importance of telling people their diagnosis, the stigma and negative impact of the diagnosis appeared to affect how they approached the delivery. Downplaying negative aspects of dementia and assuming lack of insight raise ethical issues about informed patient choices surrounding diagnosis and treatment. The lack of control doctors felt regarding their place in the system reflects service issues that may be important to address to improve patient experience.

# **Chapter Eight: Discussion**

The aims of this thesis were to (1) identify how diagnoses of dementia are communicated in diagnosis feedback meetings in memory clinics; (2) identify how people with dementia respond to diagnosis; and (3) explore the perspectives of doctors in communicating dementia diagnoses in memory clinics. A systematic literature review of observational studies was conducted to identify existing research and themes arising from studies of communication between people with dementia and healthcare professionals in outpatient settings. Eighty-one video recorded diagnostic feedback interactions in memory clinics in London and Devon were micro-analysed using conversation analysis. How doctors approach and deliver the diagnosis, as well as how patients respond and how these responses were managed, was described. Focus groups were held with the same doctors whose diagnosis feedback meetings were analysed to provide context from the doctor perspective.

The issues that arose throughout the exploration of dementia diagnosis delivery were complex and overlapping. Communication of a diagnosis of dementia was affected by the terminal and stigmatised nature of the condition, patient cognitive impairment, and changes in dementia awareness and policy. The findings raise important questions about dementia diagnostic communication. How can a doctor ensure that a person understands they have dementia when they are likely to have some level of cognitive impairment? How can diagnostic information be delivered both honestly and sensitively? Given the different levels of patient awareness of their symptoms, what constitutes a person's understanding of their diagnosis?

The previous chapters explored these questions as they became evident in the analysis of the diagnosis interactions. In this chapter these issues will be explored in the broader context of dementia as a condition: its status in the public sphere and the personal representations of people with dementia and their families. Following this, the findings will be discussed in the context of conversation analytic (CA) research. Lastly, the implications of the findings for dementia diagnosis delivery in practice and memory services will be outlined.

## **Perceptions of dementia and communicating the diagnosis**

### *Public awareness and the stigma of dementia*

As discussed previously, there has been a dramatic increase in dementia awareness, with a variety of initiatives aiming to improve the image of dementia and create environments where people with dementia will be supported to live independently (Alzheimer's Society, 2013, Donegan et al., 2017). In the UK, policies specifically aimed at increasing the number of people receiving dementia diagnoses have been successful in accelerating an increase in dementia diagnosis rates (Donegan et al., 2017). However, the current study highlighted the pressures that these campaigns and policy changes give rise to in daily clinical practice. This includes increased risk of making incorrect diagnoses and the focus on diagnosis rates over continuity of care causing concern about providing adequate support for patients. Additionally, the reported benefit of increasing dementia diagnosis rates have been questioned in light of the cost of changing services to accommodate these changes and the lack of corresponding improvements in post-diagnostic support (Brayne, 2017, Evans, 2014, Vince et al., 2017).

As discussed in the previous chapters, it was evident in the data that doctors were adhering to policy changes surrounding diagnosis and explicitly delivering dementia diagnoses to patients. Strategies such as using more direct deliveries with people with lower cognitive test scores, taking steps to re-reference the evidence and delineate dementia from normal ageing within the delivery, and exploring patient perspectives and understanding after the delivery showed doctors aiming to enhance patient understanding of their condition. However, the stigma of the diagnosis and its resulting negative impact dominated how doctors tell people they have dementia, from downplaying the severity of the diagnosis, to avoiding prognosis discussions and providing optimistic projections of the patients future.

The fact that an increase in dementia awareness has not led to a decrease in stigma is not surprising. Peel (2014) conducted a thematic analysis of newspaper headlines related to dementia and found a prevalence of catastrophising language (e.g. "assault", "cruel", "dreaded"), as well as a rhetoric of blame concerning ways to prevent dementia through changes in diet



and lifestyle. In a critique of dementia awareness campaigns, Swaffer (2014) argues that the language surrounding dementia is still negative (e.g. “sufferers”, “victims”), and that campaigns rarely take into account the views of people with dementia, resulting in initiatives that are more divisive than inclusive.

This stigma of dementia and negative impact of the language surrounding the condition provides context for the findings of Chapters 4-7. An example of this is related to findings regarding patient orientation to diagnosis feedback. The vast majority of the diagnostic feedback meetings contained doctor elicitation of patient orientation, and over 60% of the time patients demonstrated some lack of orientation. However, as the doctors discussed in the focus groups, there is some question as to whether patients are ever adequately oriented to the dementia diagnosis before the meeting. The letters inviting patients to their appointment (Appendix B) do not mention dementia, and the majority of clinics do not offer routine pre-diagnosis counselling to discuss the diagnosis and its implications. Doctors even felt that the name “memory clinic” is not helpful, and that “dementia assessment clinic” would aid patient expectations. The avoidance of explicit discussions of dementia prior to the diagnosis delivery and the use of euphemisms (memory clinic, memory problem) is a reflection of this stigma.

The language used when discussing dementia has to change in order to reduce stigma (Swaffer, 2016), and this is especially important at diagnosis. Clinicians have a key role in challenging the stereotypes surrounding clinical conditions (Lauber et al., 2004). The current study demonstrates that doctors are discussing the diagnosis positively in terms of “living well” and accessing medication and support, which is commendable in empowering patients and their families in managing the condition. However, the use of generalised language and avoidance of specific consequences of dementia suggests an underlying anxiety surrounding communication of the diagnosis to patients, which also emerged in the focus groups. These are indications of underlying beliefs about dementia that have been discussed in studies of GP perceptions of the condition, which describe a “perceived lack of reciprocity” of people with dementia (Gove et al., 2016). This belief encapsulates the view that people with dementia have an impaired ability to reciprocate not only in one-on-one

interaction but also in society as a whole, and thus their societal value is diminished. This has been described as “therapeutic nihilism”, where doctors do not believe that a life with dementia can be a positive one, and this affects their communication around the diagnosis (Werner et al., 2013). This reflects what Swaffer describes as her experience of dementia diagnosis, which consisted of “*prescribed disengagement*” from society (Swaffer, 2015). This term resulted from doctor communication around her diagnosis of dementia, focussing on creating wills, making end of life plans, and stopping activities that gave her life meaning. She argues that a focus on the limiting aspects of dementia from healthcare professionals lowers self-esteem and increases a sense of loss.

As evidenced in the focus group discussions, doctors are aware that they do not want to “scare” patients. However, they feel under pressure to cover certain topics within diagnosis feedback, including the negative consequences of a diagnosis such as stopping driving. There is an importance in discussing these aspects of dementia in order to not set unrealistic expectations for patients and their families and encourage adjustment with potential negative future experiences (Sabat et al., 2011). However, in order for doctors to play their part in decreasing the stigma and negative perceptions surrounding dementia, it may be that a different approach to diagnosis needs to be considered – one with a balance between encouraging people to not let the diagnosis impinge on their sense of self and enjoyment of life and putting in place coping mechanisms for when the condition progresses. There is increasing literature on the effect of public perceptions and societal stigma on people’s personal experiences of dementia (Gorska et al., 2017), but little recognition of how this can be positively utilised in clinical practice. The findings from this thesis show that these broader negative views of dementia are affecting diagnostic communication, and it would be beneficial to address these, both on a structural and individual level.

#### *Individual experiences of dementia diagnosis*

The doctor-patient interaction, by its nature, is asymmetrical (Heritage and Drew, 1992). This is particularly the case in diagnosis deliveries as medical diagnoses are an area where doctors, with their medical training have epistemic authority (Heritage, 2012, Maynard and Frankel, 2005). This is salient in

conversation analytic (CA) studies in other settings, where patient input in to diagnosis discussions has been shown to be minimal compared to other parts of the consultation, such as history taking or treatment decision making (Maynard, 2003a, Stivers, 2002, Stivers, 2005). The findings in Chapters 6 show doctors are encouraging patient input into diagnostic discussions, eliciting a response to the diagnosis once delivered. While the frequency of these behaviours have not been recorded in other studies, it appears that doctors delivering dementia diagnoses are doing this more than those delivering diagnoses in other settings (Gill and Maynard, 1995, Monzoni and Reuber, 2015), which as discussed may be a method of gauging engagement in the following treatment discussions. However, as the data shows, the input of patients is still not extensive, and doctors will move on to treatment discussions often without addressing potential concerns or reactions to the diagnosis.

While the process of adapting to diagnosis takes place over time, studies show that the dementia diagnostic feedback meeting is a key transition point for patients that can influence subsequent wellbeing (Aminzadeh et al., 2007, Vernooij-Dassen et al., 2006, Mate et al., 2012, Frank and Forbes, 2017). The focus on the methods doctors use to deliver dementia diagnoses has resulted in little exploration of the patient's experience of the dementia diagnosis process in the previous 4 chapters, but an examination of this interaction is important to begin the discussion of what aspects of this interaction may affect patient experience.

Early arguments that dementia diagnosis disclosure would cause extreme negative reactions have been disproven, with some studies conversely showing a lessening of anxiety after diagnosis (Carpenter et al., 2008, Aminzadeh et al., 2007). However, the process of recognition and receiving medical help for the symptoms of dementia are associated with feelings of uncertainty – often as a result of trying to accept change while holding on to how life has been until this point (Gorska et al., 2017, Campbell et al., 2016, Robinson et al., 2005). The changes brought about by dementia can threaten people's sense of self and challenge social relationships (Mazaheri et al., 2013, Harris, 2008). Experiences will vary according to contextual factors such as gender, culture, or social class (Mazaheri et al., 2013, Tolhurst and Weicht, 2017, Jones, 2017), and people's

perspectives on their diagnosis will change over time (Vernooij-Dassen et al., 2006).

Doctors spoke of the importance of naming the diagnosis to patients, but that a key aim was to instil a positive outlook, which was also reflected in the data. A balance between honesty and hope is how people with dementia and their companions report wanting to hear the diagnosis (Mastwyk et al., 2014). However, in reality, what people take away from dementia diagnosis delivery is more complicated. People with dementia have been shown to have a variety of different explanations as to the cause of their illness, from biological descriptions about brain changes, to social factors such as retirement or living alone, to psychological factors such as low mood (Harman and Clare, 2006, Cahill et al., 2008). That doctors approached the diagnoses in a variety of ways – framing it in discussions about patient history or cognitive tests or brain scans – may contribute to these differing representations. Furthermore, evidence shows that while people may not retain the name of their diagnosis, they will remember other aspects of diagnostic disclosure (Robinson et al., 2011). For example, people with dementia may have stronger reactions to practical consequences of the diagnosis, such as having to stop driving or whether they will need to move house, than they will to the diagnostic label itself (Lishman et al., 2016, Byszewski et al., 2007, Campbell et al., 2016). The attention that doctors pay to approaching the diagnostic label, the “little dance” and strategies used to maximise understanding, may therefore need to be re-considered in relation to what patients take away from diagnosis delivery. Hence, while the use of the diagnostic label is important, the communication of the wider context surrounding receiving a dementia diagnosis – such as the explanations of the testing and the progression – needs to be approached with similar care. Evidence shows that doctors hold a belief that patients need to understand and accept their diagnosis to achieve a sense of wellbeing (Vince et al., 2017). However, it may need to be recognised that this understanding and acceptance of having dementia does not necessarily equate to understanding and acceptance of the diagnostic label, but a broader knowledge of the impact of the condition on daily life.

Doctors spoke often of the challenges in communicating with patients when they lacked “insight” into their dementia symptoms. Terminology such as “insight” can be negative in that it characterises demonstrations of unawareness of symptoms as a neurologically based symptom of the dementia, ignoring the cognitive and psychosocial factors contributing towards denial as a psychological defence mechanism (Clare, 2002). This results in labelling the person with dementia with further cognitive impairments above that of their memory or concentration problems (Bond et al., 2002). A person receiving a dementia diagnosis may be experiencing changes in their behaviour that they may feel are shameful or embarrassing, for example forgetting people’s names, or making mistakes while driving. The fact that in conversation with doctors people may avoid talking about these behaviours, or normalise them as a part of ageing, is not surprising given our natural desire to protect our own self-image in social contexts (Sabat and Harre, 1992, Goffman, 1967). Denial of dementia may occur after the diagnosis as much as before, both as a coping strategy (Harman and Clare, 2006) and as a cognitive response to the receipt of “threatening” information (Christopher and Cheston, 2015). The danger of speaking of patient ‘insight’ is that it categorises these face-saving strategies as a part of the person’s dementia, and thus a permanent part of their psychological state. If patient denial of their symptoms, or reluctance to speak of ‘shameful’ aspects of their experiences, is considered instead as part of their coping mechanism for their illness, the challenges in communication could be overcome with encouraging a safe environment for people to talk about their difficulties (Cheston, 2005).

Research shows that personal representations of illness have implications for coping and management (Clare et al., 2016), and thus doctors’ explanations of the diagnosis on delivery are likely to have similar implications. If doctors are withholding certain aspects of the diagnostic information this will cause uncertainties in how people view and thus develop strategies to live with the condition (Harman and Clare, 2006). An emphasis on the positive aspects of a diagnosis can result in people being unable to acknowledge feelings of distress or loss, or not accepting a need for change (Bartlett et al., 2017). The analysis in Chapters 5 and 6 show specific aspects of the diagnosis delivery that may contribute to this – such as downplaying the severity of the diagnosis and

avoiding prognosis discussions. While the prognosis of dementia will need to be approached sensitively, it is likely that a clearer discussion of the potential impacts of dementia will help with feelings of uncertainty. Similar issues have been discussed in oncology settings (Maynard et al., 2016, Leydon, 2008). The avoidance of prognosis discussions raises ethical issues on the patient's right to know and plan for the future, and these need to be addressed not only in dementia, but in the wider medical context (Hancock et al., 2003).

A change in clinical perceptions of people's experiences of dementia is thus integral in improving communication about diagnosis. There is a long tradition of psychosocial understandings of dementia, where dementia is defined not in medical terms, but in terms rooted in patient experience (Keady and Nolan, 1995, Sabat, 2001, Clare et al., 2012). Pratt and Wilkinson (2003) describe two axes of patient understanding of dementia diagnoses – one representing a spectrum of “the desire and ability to know the diagnosis” from high to low and one representing the social context of the diagnosis from negative to positive (including stigma, support, and medical practices). These axes form 4 quadrants of patient understanding and experience of diagnosis: detachment (low ability and desire to know, negative social context), distress (high ability and desire to know, negative social context), maximising coping strategies (high ability and desire to know, positive social context), and decline and denial (low ability and desire to know, positive social context). The authors give examples of how this can aid clinical practice that is suited to individuals – for example if someone is experiencing distress from a desire and ability to know their diagnosis but a negative social context in having little access to support, clear diagnostic information may help their distress. On the other hand, if a person is in a state of denial and not interested in knowing the diagnosis, but has a positive social context of family and professional support, then in-depth diagnosis discussions may be less beneficial. It may be that the use of models such as this, that place the patient's experience central to diagnosis disclosure, may enable clinicians to approach diagnosis delivery in a way that is truly timely according to the individual with dementia.

## Contribution to Conversation Analysis Research

In CA studies of medical interaction, diagnosis delivery has not been as extensively studied as other aspects of medical communication such as treatment recommendations and problem presentations (Sidnell and Stivers, 2013). Where it has been studied, the majority of the settings were in primary care, where the conditions are usually less complex, and issues affecting the communication, such as patient accounting for visiting the doctor and the conduct of physical examinations, are different from secondary care settings. There has been extensive study by Maynard and colleagues (Gill and Maynard, 1995, Maynard, 2006, Maynard, 2004, Maynard, 2003a, Turowetz and Maynard, 2016) in developmental disabilities settings, as well as studies in oncology (Leydon, 2008, Maynard, 2006), neurology (Monzoni and Reuber, 2015, Monzoni et al., 2011b) and psychotherapy (Peräkylä, 2011), which suggest many parallels with the current findings. These will now be discussed, followed by a discussion of intersubjectivity in dementia diagnosis interactions.

### Comparison of dementia diagnosis delivery with diagnosis delivery other settings

These studies show that there are many similarities between how doctors deliver and how patients respond to diagnosis across different settings, providing evidence of the 'norms' of diagnostic interaction that characterise delivery of a medical diagnosis.

As discussed above, there may be many overlapping reasons why patients receiving dementia diagnoses resist doctor formulations of their symptoms that are the same as other conditions, i.e., stigma, denial, and a desire to save face. Doctor epistemic authority is threatened by patients who are misaligned to the purpose of the diagnostic meeting and/or the doctor's formulation of their symptoms. However, when there was misalignment, patients still showed adherence to the doctor's authority: commonly presenting examples of where they are functioning well and thus indirectly contradicting the doctor's formulation rather than explicitly disagreeing ("*I remember an awful lot of things*" extract 11 Chapter 4). This is similar to how resistance occurs in other

diagnostic settings, where patients provide further information after diagnosis that is contrary to the diagnosis being delivered (Maynard, 2004, Stivers, 2005, Peräkylä, 2002).

The delicacy that has been described in other breaking bad news interactions is evident in dementia diagnosis feedback (Maynard, 2003). The terminal and stigmatised nature of a dementia diagnosis meant that it was approached with delicacy with evidence of qualification and mitigation, as well as optimistic projections and avoidance of prognosis discussion. There was however also evidence of doctors approaching the diagnosis directly in order to maximise understanding in the face of cognitive impairment. Inferential diagnosis deliveries (“this is dementia”) were most common, as described in other settings (Maynard, 2003b, Monzoni and Reuber, 2015). However, that doctors used direct deliveries (“you have dementia”) more often with people with lower cognitive test scores indicated that in some cases doctors prioritised clarity over sensitivity in telling people their diagnosis.

What has also been described in other settings, but may be particularly relevant to memory clinics, is doctors displaying accountability for their knowledge about the patient. As described in Chapter 4, challenges can arise if the doctor demonstrates claims to knowledge without accounting for that knowledge (“*so your memory problems started 9 months ago?*” Extract 9) when that information came from the patient’s family rather than the patient themselves (“*I never said that!*” Extract 9). Additionally, doctors displayed evidence from the testing to account for diagnoses, which has been described in other settings as particularly common when the testing process is “opaque” to patients (Peräkylä, 1998). This is particularly the case in dementia, where there are multiple tests and sources of information before clinicians make a diagnostic decision. That doctors often repeated evidence from the testing or rationale for diagnosis in the pre-diagnosis location provided further accountability for the diagnosis. That this was so frequent in the current data could be a method for doctors to retain accountability when patients may have not been able to hold the information in working memory. However, the repetition of previously fed back test results in the diagnosis sequence has not been systematically described in other settings. Hence, no clear conclusion can be drawn as to whether this is a strategy to



combat potential memory problems or whether this is a feature of diagnosis feedback more generally.

Initial responses to the diagnosis were similar to that reported in other settings (Heath, 1992, Peräkylä, 2005, Maynard, 2003a). The majority of patients responded minimally, i.e., with minimal acknowledgement tokens (mhm), non-verbal gestures such as nodding, or with no verbal or non-verbal reaction. However, doctors pursued patient extended responses to the diagnosis delivery more than has been reported in other settings, particularly in primary care where patient responses are very rarely oriented to as important. This enabled a study of the relation between initial responses and responses after pursuit: this demonstrated that minimal responses marked by stress or intonation were more likely to lead to extended, often resistant, responses later in the meeting. Additionally, those who later showed resistance had initially responded displaying disinclination to continue the discussion, demonstrating the importance of stoicism in the interaction. While these patterns have been analysed in the CA literature (Maynard, 2003a, Heritage, 2009), it has not before been examined quantitatively. It appeared that eliciting the patient's perspective was sufficient for the progression of the meeting, and that achieving understanding was not a key objective in these meetings. This is similar to other settings where diagnoses may be contentious, such as neurology and developmental disabilities (Maynard, 2004, Monzoni et al., 2011b).

### *Intersubjectivity in dementia diagnostic interactions*

Intersubjectivity concerns how participants in interactions aim to negotiate and maintain a mutual understanding of their "*intentions, their state of knowledge, their relation, and their stance towards the talked-about objects*" (Peräkylä, 2007, p1). CA examines intersubjectivity in how speakers display understanding of each other's talk within the structures of interaction. As a simple demonstration, a current utterance displays an understanding of a prior utterance: if an utterance is hearable as an answer, this demonstrates the speaker's understanding of the previous turn as a question. Hence, a misunderstanding of the previous turn can cause the original speaker to re-state his turn or pursue the appropriate response in order to ensure a mutual

understanding (Sacks et al., 1974). Studies of interaction where one person has dementia in the later stages demonstrate a particular challenge for intersubjectivity due to potential impacts of dementia on memory, attention, and language processing, as well as a lack of flexibility in the person without dementia to alter their communication (Jones, 2013, Müller and Guendouzi, 2005).

The findings of this thesis relate to intersubjectivity in dementia diagnosis feedback interactions. The data presented in Chapter 4 indicated that there was often misalignment in doctor and patient perceptions of the purpose of the meeting. This became evident because doctors, implicitly or explicitly, took steps to gauge patient perspectives as to the purpose of the meeting and their experience of their symptoms – thus displaying an aim to achieve intersubjective understanding. When misalignment did occur, doctors implemented practices to negotiate and come to an agreement regarding the dementia diagnosis. As discussed above, many of these practices were the same or similar to practices used in other interactional settings: building diagnoses from the patient's perspectives, delivering the diagnosis through inference, and pursuing a response (Turowetz, 2015, Maynard, 2003a, Monzoni and Reuber, 2014).

However, over half of patient responses to diagnosis even after pursuit were either explicitly resistant, or were minimal or topic-shifting indicating passive resistance (Stivers, 2005). Hence, patient expression of agreement with the diagnosis was more often not achieved than achieved within the diagnosis feedback meeting. As discussed in Chapter 6, this remaining misalignment did not affect the successful progression of the interaction from diagnosis to treatment discussions. What this suggests from a CA perspective is that intersubjectivity within the diagnosis delivery and receipt does not reflect explicit agreement or acknowledgement on the part of the patient. This adds to previous arguments that patients do not see the primary purpose of medical examinations to be diagnosis, but instead are primarily oriented to accessing desired treatment (Robinson, 2003b, Stivers, 2002). Research on the implications of not reaching intersubjective understanding on the nature of

dementia regarding potential resistance to treatment and support would develop this further.

### **Implication for Practice and Services**

In the mid 1990s Keady was arguing for dementia services to be structured according to the needs and experiences of the person with dementia (Keady, 1995). However, reflecting on the findings from Chapters 4-6 in the light of research demonstrating the complex experience of dementia diagnosis on individuals, it appears that, despite 20 years passing, there are still barriers to person-centred care that appear to be at least partially caused by service structure.

As discussed in the introduction, the current clinical guidance for memory clinics provides very little detail on how to communicate dementia diagnoses. The most specific guidance is from the British Psychological Society (Murphy and Gair, 2016), which emphasises checking patient preferences and understanding, using diagnostic terms, and allowing time for patients to process diagnostic information. While it is important to highlight these points, the guidance does not offer further instruction in terms of how these communication practices can be achieved, given the busy clinical context and complexities of interacting both with people with dementia and their families.

This thesis did not aim to identify best practice in that it did not systematically examine the effects of different interactional practices on patient outcomes. However, there are challenges identified in the communication of dementia diagnoses that may have implications for practice and services:

1. *Doctors and patients meeting for the first time in diagnosis feedback*: one of the key challenges reported by doctors was trying to identify the needs and expectations of patients (and their companions) when they had not met previously. This was also evident in the data, with doctors eliciting orientation to the purpose of the meeting and perception of symptoms in order to approach the diagnosis according to the person's expectations. Meeting for the first time also caused doctor concern about diagnostic

accuracy, with some doctors feeling uncomfortable with using reports from other clinicians to make diagnoses of early stage dementia. While systems such as in Site A where the testing and feedback on the same day might be convenient for doctors and patients, the resulting lack of established relationship between the doctor and patient could be causing barriers to diagnostic decision making and communication. Studies also suggest that patients and families prefer hearing dementia diagnoses from a professional who they have a relationship with, regardless if they have dementia-specific expertise (Robinson et al., 2011, Keady et al., 2005).

2. *A lack of pre-diagnostic counselling:* Doctors reported that they were not always sure if patients knew they were being investigated for possible dementia when they started the memory clinic process. Guidelines highlight the importance of pre-diagnostic counselling in dementia diagnosis (Hodge et al., 2014, Guss, 2014), but in this study of 9 memory clinics only one had systematic pre-diagnosis meetings in place. That over 60% of people attending the clinic showed some confusion as to the purpose of the meeting is likely to be compounded by the lack of explanation prior to the diagnosis meeting in addition to memory difficulties and disorientation. Patients report being unaware that they have been referred for assessment and finding the testing process a 'labyrinth' without clear explanations from professionals (Samsi et al., 2014, Cahill et al., 2008). If doctors know that patients have received clear explanations of what to expect, then they may not have to undertake this 'little dance' when it comes to the communication. Additionally, expectation may mitigate difficult reactions to the diagnosis or its life-altering consequences, such as cessation of driving.
3. *Confusion in test feedback:* The data presented in Chapter 4 demonstrated that, while doctors used test results to successfully forecast the diagnosis to come, there could often be some confusion in their communication. It was evident that explanations of the test were causing misunderstandings in the diagnostic feedback (e.g. extract 5 in Chapter 6 where the tests were described as "*not too bad*" but the patient received a diagnosis), and this has also been reported in studies of patient experience of receiving feedback from assessments (Keady and Gilliard, 2002). If clear explanations

are given of the purpose of each test as it is being conducted, and doctors report the results with clear assessments as to their meaning for diagnosis, then this might remove some of the uncertainty and misunderstanding that this leads to.

4. *Minimising or avoiding negative aspects of diagnosis*: Doctors emphasised that instilling hope was an important consideration in the diagnosis delivery (“*I want them to understand but not too much*” H21). This was evident in the video recordings, with doctors shifting the diagnosis discussion to treatment and support discussions by giving the diagnosis a positive slant. This has also been discussed in the literature (and the systematic review in Chapter 2): debating whether honesty is the best policy in communicating with people with dementia, or whether the facts of the matter may cause too much unnecessary distress (Lindholm, 2015, Dooley et al., 2015). However, given that there are also concerns about a lack of post-diagnostic support, it may be that avoidance of the negative aspects of dementia will result in the patient never having a chance to talk about the prognosis, or process the potential anxieties about the diagnosis, with a healthcare professional. This may result in misunderstandings and cause particular challenges as dementia progresses (Stokes et al., 2014, Read et al., 2016).
  
5. *Misaligned doctor and patient agendas*: Doctors raised the important point that it is difficult to discuss the diagnosis and prognosis in too much detail given the pressing medical agenda in the diagnostic feedback meeting. They describe having to cover certain topics in diagnosis feedback, such as medication, power of attorney, and driving. It was evident from the data that patients also have their own concerns that are on their agenda to discuss with the doctor, for example bringing up their medication (P150\_H41), or shifting the topic to physical health conditions immediately after diagnosis. Patients report being disappointed with receiving a dementia diagnosis as the outcome differs from potential expectations of receiving support or treatment (Karnieli-Miller, 2012): this is also an issue that could be addressed in pre-diagnostic counselling. Additionally, while it was clear that doctors had clear agendas in terms of what they wanted to discuss with patients, it may be that flexibility in what has to be covered in diagnosis

feedback and what could be covered in later meetings could alleviate some of the time pressure surrounding communication of the diagnosis.

6. *The availability and quality of post-diagnostic support:* While all of the memory clinics in the study had systems of post-diagnostic support – such as meetings with dementia practitioners or support workers, or referrals to cognitive stimulation therapy – there was little consistency. Doctors expressed concern as to the quality of support given, and were relieved when they knew patients would be staying within their clinical teams and they could follow them up personally if needed. Again, guidelines highlight the importance of post-diagnosis support (Hodge et al., 2014, Guss, 2014). Patients and their families report only starting to consider practical implications and needs in the months after receiving a diagnosis (Campbell et al., 2016), highlighting the importance of post-diagnosis support for people in adjusting to the diagnosis and condition. If systematic, personalised post-diagnostic support is given, with continuity from diagnosis feedback in terms of clinicians and information provided, then there may be less institutional pressure to cover certain topics in the diagnosis feedback meeting. This could facilitate more space to explore perspectives and understanding of diagnosis and prognosis, thereby allowing patients and companions an opportunity to process this life-changing turning point in the dementia journey.

## **Strengths, Limitations, and Future Research**

### *Strengths and Limitations*

The strength of this thesis is the combination of a large dataset and detailed microanalysis of dementia diagnosis interactions. The use of data collected across 4 NHS trusts, with 20 doctors and 81 patients, allowed enough variation in doctor communication style and patient characteristics to identify systematic patterns in how dementia diagnoses are delivered. Conversation analysis, a well-established, rigorous method to analyse communication, enabled a detailed, inductive description of the practices used by doctors and patients as they approach and manage the challenges surrounding dementia diagnosis. The systematic review of the existing literature examining communication

between clinicians and people with dementia in outpatient settings and the findings from the focus groups with the doctors provided a wider context for the CA descriptions of the interactions.

The main limitation of this thesis is the lack of detailed study of the role of the patient's companion in the meeting. The difficulty in managing the patient's needs alongside their companion's was a topic highlighted in both the systematic review and the focus group study. Although companions played a larger role in the later stages of the meeting than the diagnosis delivery, a study of how and when companions become recruited for participation in the diagnosis delivery would have been a useful complement. However, the rigorous and time-consuming nature of the in depth qualitative data analysis, alongside the large number of diagnostic meetings analysed, meant that only certain aspects of the diagnostic interaction were within the scope of this thesis.

The second main limitation of this thesis is the lack of focus on the patient perspective. Given the research questions focus on how doctors deliver a diagnosis of dementia, doctors' perspectives were explored. Ideally patients' and companions' perspectives would have complemented the video data and focus groups with doctors, but this was beyond the scope of this PhD study.

A central assumption of CA is that the meaning of talk is contained within that which is displayed to participants in the context of systematic interactional structures. Within this thesis meaning was therefore taken from within the analysis of the talk, and was approached without reference to other potential outcomes such as measures of patient and companion satisfaction or experience. Additionally, CA seeks to describe patterns of particular actions having particular consequences within interaction. Hence, there was no labelling of 'good' or 'bad' practice in the communication of dementia diagnoses, which could be considered a limitation of the thesis. Further research using perspectives of people with dementia, their companions, and professionals, alongside further work examining diagnosis delivery practices will be needed to start making conclusions about best practice.

Doctors knew that they were being video recorded. In recruitment discussions researchers described the study as having a focus on doctor-patient communication. Doctors will perhaps have been more aware of their communication than if they were not recorded. Patients and companions were also aware they were being filmed and their communication was being analysed, which may have affected their behaviour in the consultation.

In terms of the validity and generalisability of the study, the literature review followed a systematic approach, with multiple reviewers ensuring a rigorous search and analysis of the available literature. Additionally, the focus group analysis was rigorously conducted within the research group, and inter-rater reliability in coding the data was high. Conversation analysis methodology was followed, with the next turn-proof procedure, repeated analysis in data sessions, and explorations of deviant cases ensuring a transparent and rigorous analytic process.

### Future Research

The findings of this study are relevant to the recent government policies encouraging early and timely diagnoses, and the utility of disclosing a diagnosis of dementia. The primary reason for the push to increase diagnostic rates at the early stages of dementia is to encourage future planning at the earliest stage possible: for doctors to ensure that patients have power of attorney, wills, and advance care plans in place while they still have capacity. However, this study has highlighted the difficulty in telling people they have dementia and thus will need to make plans for when they will no longer be able to make decisions, but also ensuring that people live well despite their diagnosis. This is compounded by the variety of awareness and acceptance of symptoms of people in early stage dementia, which means companions often will have been more pro-active in seeking help. The analysis of diagnostic interactions demonstrates that for most doctors working currently in memory clinics, despite the change of policy to increase diagnoses, a key concern is to ensure that patients leave meetings with a positive future outlook.

Future research needs to address this dilemma. An important question is whether patients not explicitly accepting the diagnosis, or doctor avoidance of



prognosis, have an effect on whether patients agree to and engage in treatment and support. Previous research has shown that diagnosis discussions are predominantly focused on progressing to treatment discussions (Robinson, 2003a), and thus the fact that doctors do not pursue agreement with the diagnosis might indicate this it is not necessary to discuss treatment effectively. However, a detailed analysis of how patients display awareness of symptoms and understanding of diagnosis pertain to the later stages of the meeting, and to post-diagnostic meetings, and would be an important development of this work.

Additionally, given that the role of the companion and the difficulty of triadic meetings have been highlighted in the literature, the role of the patient's family members and friends in the diagnostic interaction would be an interesting topic for future study. As noted above, the findings from the review indicate that the input of the companion is likely to have an impact on how people with dementia are involved in diagnosis discussions and treatment decisions. As this triadic communication has been identified as a challenge for clinicians, it would be important to identify how doctors are currently managing this in memory clinics, in order to inform future research and guidelines.

Another interesting and important area for future research would be the examination of how different diagnoses are delivered in the memory clinic. As touched upon in the introduction, people can leave memory clinics with diagnoses of functional memory problems, mild cognitive impairment (MCI), as well as no diagnosis. There is some evidence that the push for increased diagnosis rates has led to an increase in the "*worried well*" attending memory clinics, and that this is a challenge for clinicians (Blackburn et al., 2014). MCI has also been identified as an ill-defined and complicated diagnosis to make – with a lack of clarity as to whether it is a step between normal ageing and dementia, or a condition in its own right. Additionally, CA studies of people who receive no diagnosis from diagnostic meetings have reported a "*symptom residue*" – i.e. patient concerns that have not been addressed (Maynard and Frankel, 2005, :251). An examination of how doctors address these challenges in communicating non-dementia diagnoses to people attending the memory

clinic, and a comparison with the delivery of dementia diagnoses, would be an important topic for future research.

Future research could also examine diagnostic deliveries with a focus on differences according to dementia subtype and participant characteristics. While there was not a clear difference in the cases where patients had lower cognitive test scores (except in the direct or inferential deliveries) or ages in this sample, these patients were not in the majority. For example, there was only one patient under the age of 65 in the sample, and further observation of the delivery of young onset dementia diagnoses may show some important differences. Furthermore, there was a lack of ethnic diversity between the patient and companions recruited to this study. Diagnosis delivery may be different, and more challenging, with people from non-Western cultures who may have different awareness of dementia. The issues that arose in the analysis of the diagnosis discussions may have had different consequences in interactions with people with different backgrounds, and this would be interesting to explore in future research.

### **Concluding remarks**

A dramatic shift in policy emphasising an individual's right to know their diagnosis and plan for their future has led to diagnosis rates increasing rapidly. Receiving a diagnosis of dementia enables people to have access to support, as well as giving them and their families a medical explanation for symptoms. This in-depth analysis of doctor communication of dementia diagnoses demonstrated the dilemma of diagnosis delivery. While doctors were observed to use practices to enhance patient understanding, these were counterbalanced by an emphasis on positive outcomes and a downplaying of prognosis that may preclude understanding. This reflected an aim to ensure patients are fully informed of their diagnosis while also maintaining an optimistic outlook. However, this was compounded by the challenge of gauging patient expectations and perspectives in the context of meeting them for the first time.

An important factor in the delivery and receipt of a dementia diagnosis is that it is a process. A dementia diagnosis is something that will take time to

understand, both for the person with dementia and their companions. The diagnosis delivery is a stage in the journey that starts with a recognition of symptoms and continues to the acceptance of help and support. Dementia services should reflect this journey, with appropriate support and information available at different stages of the condition. While there has been much focus on ensuring that everyone who has dementia is told their diagnosis, it is equally as important to ensure that support is in place in the weeks, months and years after a person receives a diagnosis of dementia.

# Appendices

## Appendix A: Quality Assessment Tool: Critical Appraisal Skills Programme (CASP)

### Qualitative Research Checklist

**\*\*Answer all questions either YES, NO, or CANNOT TELL**

#### Screening Questions:

(If either are a “no” then do not continue)

1. Was there a clear statement of the aims of the research? Consider:
  - *What the goal of the research was.*
  - *Why is it important?*
  - *Its relevance.*
2. Is a qualitative methodology appropriate? Consider:
  - *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.*

#### Detailed Questions:

3. Was the research design appropriate to address the aims of the research? Consider:
  - *If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?*
4. Was the recruitment strategy appropriate to the aims of the research? Consider:
  - *If the researcher has explained how the participants were selected.*
  - *If the data has given clear descriptions of number of eligible patients, patients approached and those consented.*
  - *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.*
  - *If there are any discussions around recruitment (e.g. why some people chose not to take part).*
5. Were the data collected in a way that addressed the research issue? Consider:
  - *If the setting for the data collection was justified.*

- *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
  - *If the researcher has justified the methods chosen.*
  - *If the research has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?*
  - *If methods were modified during the study. If so, has the researcher explained how and why?*
  - *If the form of data is clear (e.g. tape recordings, video material, notes etc.)*
  - *If the researcher has discussed saturation of data.*
6. Has the relationship between researcher and participants been adequately considered? Consider:
- *If the researcher critically examined their own role, potential bias and influence during:*
    - *Formulation of the research questions.*
    - *Data collection, including sample recruitment and choice of location.*
  - *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.*
7. Have ethical issues been taken into consideration? Consider:
- *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.*
  - *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects on the study participants during and after the study)*
  - *If approval has been sought from the ethics committee.*
8. Was the data analysis sufficiently rigorous? Consider:
- *If there is an in-depth description of the analysis process.*
  - *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?*
  - *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.*
  - *If sufficient data are presented to support the findings.*
  - *To what extent contradictory data are taken into account.*

- *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.*

9. Is there a clear statement of findings? Consider:

- *If findings are explicit.*
- *If there is adequate discussion of the evidence both for and against the researcher's arguments.*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst).*
- *If the findings are discussed in relation to the original research question.*

10. How valuable is the research? Consider:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding, e.g. do they consider the findings in relation to current practice of policy, or relevant research-based literature?*
- *If they identify new areas where research is necessary.*
- *If they identify any limitations to the study. Do identify further areas but limitations not described in overt detail.*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.*

## Appendix B: Examples of Memory Clinic Appointment Letters

### Site A:

#### (Site A) Early Assessment Clinic

Dear Mr/Mrs (name),

#### Referral to the (Site A) Clinic

Further to your recent appointment with your GP we have received a referral for you to visit us at our Memory Clinic.

The purpose of the Memory Clinic is to assist people in (Site A) who may have problems with memory. Later, when we have a clear understanding of your circumstances we may be able to advise you on ways of helping with the memory difficulties.

**It is important for another person who knows you well to come along with you to your assessment. A member of our team will spend time talking with them to get their perspective and views of your potential memory problem.**

Your appointment will start with a CT scan in the hospital's radiology department at (Site A), followed by a memory assessment in the clinic.

CT (Computerised Tomography) is an x-ray scan that creates a series of images showing cross sections through the head or body. During the scan you will be asked to lie on the scanner and remain very still (movement will blur the images). The scan does not hurt nor have unpleasant side effects. The whole procedure commonly takes approximately 10 minutes.

Your CT scan appointment details are as follows. Following the scan, a member of the team will direct you to the Memory Clinic which is based at Medical



Outpatients South (Site A). During the assessment you will see members of the medical, nursing and psychology teams.

Date of Appointments: **Date**

### **1. Scan Appointment**

Time of Appointment: **09:00AM**

(If possible please arrive 15 minutes before your appointment time.)

Location: (Address)

### **2. Memory Clinic Appointment**

Time of Appointment: **09:30am**

Location: (Address)

The entire assessment will last approximately between 2½ or 3 ½ hours.

You and the person supporting you with this appointment will meet with different team members to ensure we get a full understanding of the issues you are experiencing from both perspectives. The details of this will be explained to you both when you arrive at the clinic.

#### **On the day:**

**Please bring with you a list of any medication that you are currently taking.**

**Please bring this letter to your appointment.**

**If you wear glasses for reading, or a hearing aid, please bring them with you.**

Anything you discuss and disclose during your appointment is confidential, although we are required to send a written report to your GP.

### **Parking arrangements**

There is a pay and display car park at the Hospital. Alternatively, we are able to give you a parking permit for the (name) site from where you can walk through the grounds to the (name) site. If you would like a parking permit please telephone our office at least one week before your appointment and we can arrange for one to be issued.

Should you need to cancel or change this appointment, please telephone the clinic as soon as possible on 01392 406103

Yours sincerely

(name)

Memory Clinic Administrator

**Site B:**

**Services for Ageing and Mental Health**

Dear (name),

An appointment has been made for you to see Dr (name).

ON: **DATE at TIME**

AT: **CLINIC ADDRESS**

**Please let me know on the above telephone number if you cannot attend this appointment as soon as possible so we are able to offer the slot to another patient.** If you wish to contact me on the morning of the appointment only, the telephone number for the day hospital is (number). At any other time I can be contacted on the number at the top of the page.

The nearest buses are (address), the (address), or the (address). Please give me a ring if you need further directions.

We teach (university) medical students. When you attend the clinic you may be asked if you mind having medical students sit in on your appointment. If you are attending for the first time you may also be asked if you will talk to medical students first and if you agree they will ask you about your current problems and about your past, and they will tell a senior doctor what you have told them who will then also see you. If you don't want medical students to sit in on your appointment or for them to see you, please tell either the receptionist or the doctor either when you arrive at the appointment, when approached or you can also ring in advance.

**Please bring a list of all current medication.**

Yours sincerely,

(name) **Team Secretary**

## Appendix C: Jeffersonian Transcription Notation

(Maynard and Frankel, 2005, :251)

Symbol	Meaning
[ text ]	Indicates the start and end points of overlapping speech.
=	No discernible pause between two speakers' turns or, if put between two sounds within a single speaker's turn, shows that they run together
(No of seconds)	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	A brief pause, usually less than 0.2 seconds.
. or ↓	Indicates falling pitch.
? or ↑	Indicates rising pitch.
,	Indicates a slight rise in intonation.
¿	Indicates a rise in intonation, more than a , but less than ?
-	Indicates an abrupt halt or interruption in utterance.
>text<	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text>	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
°	Indicates whisper or reduced volume speech.
ALL CAPS	Indicates shouted or increased volume speech.
underline	Indicates the speaker is emphasizing or stressing the speech.
:::	Indicates prolongation of an utterance.
£text£	Smiling heard in tone of voice

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hh	Audible exhalation
.hh	Audible inhalation
wo(h)rd	Word with laughter 'bubbling' in it
( text )	Speech which is unclear or in doubt in the transcript.
( <i>italic text</i> )	Annotation of non-verbal activity.

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## Appendix D: Results from Statistical Analysis in Chapter 5

### 1. Relationship between ACE cognitive test score and Minimising the Diagnosis Severity (use of terms “mild” or “early”)

#### Group Statistics

	Downgrade Severity	N	Mean	Std. Deviation	Std. Error Mean
ACE score	No	40	67.68	13.392	2.118
	Yes	25	68.68	14.314	2.863

### Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means						
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
ACE-III score	.072	.790	-.287	63	.775	-1.005	3.506	-8.011	6.001
Equal variances assumed			-.282	48.509	.779	-1.005	3.561	-8.163	6.153
Equal variances not assumed									



## 2. Relationship between ACE cognitive test scores and Diagnosis Format

### Group Statistics

	Direct or Inferential Diagnostic Format	N	Mean	Std. Deviation	Std. Error Mean
ACE-III score	Through Inference	40	70.78	13.306	2.104
	Direct	25	63.72	13.318	2.664

### Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ACE-III score	Equal variances assumed	.305	.583	2.079	63	.042	7.055	3.394	.273	13.837
	Equal variances not assumed			2.078	51.057	.043	7.055	3.394	.241	13.869

## Appendix E: Results from Statistical Analysis in Chapter Six

### 1. Relationship between Dementia Type and Initial Response

**Crosstab**

Count

		No/Minimal or Extended Initial Response		Total
		No/Minimal	Extended	
Dementia Type	Alzheimer's disease	30	15	45
	Mixed	11	3	14
	Vascular	11	1	12
	Lewy Body	1	2	3
	Dementia Unspecified	2	1	3
	Parkinson's	2	0	2
	Alcohol Related	1	0	1
	Semantic dementia	1	0	1
	<b>Total</b>	<b>59</b>	<b>22</b>	<b>81</b>

### Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	7.165 <sup>a</sup>	7	.412	.428		
Likelihood Ratio	8.389	7	.300	.427		
Fisher's Exact Test	6.884			.398		
Linear-by- Linear Association	1.397 <sup>b</sup>	1	.237	.262	.136	.036
N of Valid Cases	81					

a. 12 cells (75.0%) have expected count less than 5. The minimum expected count is .27.

b. The standardized statistic is -1.182.

## 2. Relationship between Delivery Format and Initial Response

### Crosstab

Count

		No/Minimal or Extended Initial Response		Total
		No/Minimal	Extended	
Direct or Not Direct	Not Direct	39	9	48
Diagnostic Format	Direct	20	13	33
Total		59	22	81

### Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	4.213 <sup>a</sup>	1	.040	.047	.037	
Continuity Correction <sup>b</sup>	3.234	1	.072			
Likelihood Ratio	4.167	1	.041	.074	.037	
Fisher's Exact Test				.047	.037	
Linear-by- Linear Association	4.161 <sup>c</sup>	1	.041	.047	.037	.026
N of Valid Cases	81					

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 8.96.

b. Computed only for a 2x2 table

c. The standardized statistic is 2.040.

### 3. Relationship between ACE cognitive test score and Initial Response

#### Group Statistics

	No/minimal or Extended Initial Response	N	Mean	Std. Deviation	Std. Error Mean
ACE score	None/Minimal	45	71.42	12.580	1.875
	Extended r	20	60.50	13.205	2.953

### Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ACE score	Equal variances assumed	.004	.948	3.182	63	.002	10.922	3.432	4.063	17.781
	Equal variances not assumed			3.123	34.963	.004	10.922	3.498	3.821	18.024

**4. Relationship between Asking Question (Understanding Check (UC) or Perspective Question (PQ)) or only Elaborating Information and Patient Later Response**

**Crosstab**

Count

		No/minimal or Extended Later Response		Total
		No/Minimal	Extended	
Just Elab Info or UC/PQ	No Pursuit	3	0	3
	Just Elaboration	14	20	34
	PQ or UC	12	32	44
Total		29	52	81



### Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	7.199 <sup>a</sup>	2	.027	.022		
Likelihood Ratio	8.035	2	.018	.018		
Fisher's Exact Test	6.497			.026		
Linear-by- Linear Association	5.280 <sup>b</sup>	1	.022	.026	.018	.012
N of Valid Cases	81					

a. 2 cells (33.3%) have expected count less than 5. The minimum expected count is 1.07.

b. The standardized statistic is 2.298.

## 5. Relationship between Initial and Later Response Type

**Crosstab**  
Count

		Response to Diagnosis after pursuit					Total
		None/Minimal	Question or Statement	Negative	Resistant	Off Topic	
Initial Response	None	4	2	0	3	1	10
	Non-verbal	11	4	4	1	0	20
	Minimal continuer	4	2	2	2	1	11
	Marked "mm"	2	2	0	5	0	9
	"Yeah"	3	3	0	2	1	9
	News receipt or Change of state	2	5	4	0	0	11
	Question	1	2	0	0	0	3
	Negative	2	4	2	0	0	8
Total		29	24	12	13	3	81

### Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Monte Carlo Sig. (2-sided)		Monte Carlo Sig. (1-sided)			
				Significance	99% Confidence Interval		Significance	99% Confidence Interval	
					Lower Bound	Upper Bound		Lower Bound	Upper Bound
Pearson Chi-Square	38.345 <sup>a</sup>	28	.092	.081 <sup>b</sup>	.074	.088			
Likelihood Ratio	42.540	28	.039	.066 <sup>b</sup>	.060	.072			
Fisher's Exact Test	33.191			.071 <sup>b</sup>	.064	.078			
Linear-by-Linear Association	.016 <sup>c</sup>	1	.899	.918 <sup>b</sup>	.911	.925	.462 <sup>b</sup>	.449	.475
N of Valid Cases	81								

a. 38 cells (95.0%) have expected count less than 5. The minimum expected count is .11.

b. Based on 10000 sampled tables with starting seed 624387341.

c. The standardized statistic is -.126.



## Appendix F: Focus Group Topic Guide

### *Broad themes:*

1. *Communication of a diagnosis*
2. *Decision making*
3. *Making complicated/difficult decisions together and MCA*
4. *Scenarios*

### **Pre-diagnosis**

1. How do you weigh the evidence in reaching a diagnosis (memory tests, scan, patient/carer interviews)?

### **Communication of a diagnosis: (30mins)**

1. What needs to be discussed in the diagnostic feedback session?
2. How do you make decisions about disclosure of diagnostic information?
  - a. How do you decide how much information you provide?
  - b. Are there difficulties in balancing information for different levels of understanding?
  - c. 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'?
3. Are there ever circumstances when it is appropriate to see the carer alone?
  - a. Are there situations you can recall where there has been conflict in how much patients and carers have wanted to know?
4. Have you received training in how to deliver a diagnosis?
  - a. (if discussion about breaking bad news training, then how does do you apply this in a memory clinic setting?) If you have worked in different services, have you noticed any changes in the way diagnoses are delivered? (Or have you noticed a change in this over time?)

5. Who is the primary recipient of the diagnosis?
6. What do you think about asking permission to discuss the diagnosis with the patient and companion? What is your policy on the “do you want to know?” question?
7. Often doctors are meeting patients for the first time when they give the diagnosis, what are some of the issues that this brings up? And how do you manage this?
8. Are there particular diagnoses which are difficult to communicate or seem to create confusion? (prompt further with subtypes of dementia, and non-dementia diagnoses)
9. Are there any challenges with any particular groups (for example different ethnic groups)?
10. How do patients and carers react (emotional reactions)?
11. What is it like to deliver a diagnosis of dementia?

**Shared decision making: (30 mins)**

1. What kinds of decisions are made at diagnostic feedback appointments?
2. Do you feel that patients want to be involved in decisions?
  - a. How can you tell if patients want to be involved in decisions?
  - b. How do you explore patients’ decision-making preferences?
3. What are some of the difficulties inherent to facilitating shared decision making in the memory clinic? (Can you identify any scenarios where it is difficult to include patients in decisions)?

4. How does the presence of carers or companions impact on shared decision making or patient involvement in decisions?
5. Does it make any difference depending on relationship of the carer to the patient (eg: adult child, or elderly spouse)?
6. Specific decisions (if not already covered):
  - a. How do you make/approach decisions about Medication/Cognitive stimulation therapy or other groups/Driving/Social support/Power of attorney?
  - b. How? Are any of these issues complicated by ethnic factors?
  - c. Are there any other decisions that are made in the feedback session?
7. When is the right time to discuss about advanced care planning?
8. How confident do you feel continuing to involve people in decisions when they lack capacity? When does this become difficult? (exploring the concept of assent).
9. What resources are you aware of that might assist you in involving patients and carers in decision making?

### **Closing questions**

10. What kinds of things you would appreciate help or training on in relation to feedback appointments or your work in the memory clinic?
11. Have we missed anything?





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