Volume I

Research Component

You are happy and safe: A Discourse Analysis of a Diagnostic Disclosure of Dementia

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Dedication

All praise is to Allah who makes all things possible. I am grateful for my beloved parents without whom I would not be a great many things. This is for you Abo. Yassin, your belief in me, love and support are what keep me going. I would not have been able to do this without you. Thank you. My boys, I am sorry you had to share so much of me over the past few years but I thank you for your patience. You are all amazing. Family, thank you for always being there whenever I needed you.

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I would like to thank the two NHS sites that participated in this research and particularly those practitioners who provided me with recordings of their diagnosis session. I especially thank those individuals and their family members who received a diagnosis of dementia and agreed to have such a poignant moment in their lives recorded and analysed.

I would like to thank Dr Sara Willott who provided guidance during the analysis process. Thank you for your time and advice. I would also like to thank Dr Sophie Doswell for taking the time to read my work and provide such useful feedback.

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Thesis Overview

This thesis is divided into two volumes. The first volume consists of three parts: two papers and an executive summary. In part one a systematic literature review examining the association between post traumatic stress disorder (PTSD) and dementia is provided. It contains an evaluation of thirteen papers and a discussion of the nature of the association of PTSD and dementia. In part two an empirical paper is presented. It is qualitative study of the diagnostic delivery of dementia sessions. The data is analyzed using discourse analysis. An executive summary of the both papers is also provided in part three of this volume .

The second volume contains five clinical practice reports (CPRs) undertaken over the course of 3 years whilst completing clinical placements in the National Health Service. The first report is a formulation of a woman with depression from a systemic and cognitive behavioural perspective. The second report is a service evaluation of a Community Mental Health Team against the NICE guidelines for schizophrenia. The third report is a single case experimental design of a cognitive- behavioural intervention for a young woman with Obsessive Compulsive Disorder (OCD). The fourth report is a case study of a differential diagnosis of dementia. The final report is a summary of a presentation on Schema Therapy for a young woman with psychosomatic difficulties.

Part I

A Systematic Review of the Association between Post Traumatic Stress Disorder and Dementia

Abstract

The relationship between Post Traumatic Stress Disorder (PTSD) and Dementia is evaluated in this literature review. The relationship between the two conditions is unclear and the aim of the review was to identify any association between the two and to identify the direction of that association. 13 papers were selected through an electronic search of databases followed by a hand-search of articles and then categorised as either studies which provided evidence for PTSD leading to dementia or studies that suggested the [re]emergence of PTSD following the onset of dementia . Following a description and critique of the papers' methodologies, the strength of the evidence for a directional relationship either way as well as the possibility that shared underlying factors contribute to the occurrence of both conditions are considered in the discussion and conclusion sections. At this preliminary stage in the research conclusive findings are difficult to draw, but there is enough evidence to suggest the existence of a bi-directional association between dementia and PTSD, although the evidence for an association is not equally established in both directions. There is not yet enough evidence to suggest a causal relationship in either direction. Pointers for further research and implications for clinical practice are discussed.

Introduction

Although long-standing evidence exists to suggest that stress can often improve human performance, (Staal, 2004) chronic stress is increasing recognised as having a negative impact on our health and as affecting neuronal development (Leonard, 2006). As a result of this, there is growing interest in the association between stress and dementia. Much of dementia research on stress thus far has focused on the burdens of caring for someone with dementia, with a concern either for the health of the caregiver or for the effect of caregiver stress on the well-being of individuals with dementia (Dunkin & Anderson-Hanley, 1998; Waelde et al., 2004; Bruce et al., 2005; Vitaliano et al., 2003; Gilhooly & Whittick, 2006; Bledin et al., 1990). Spurred perhaps by evidence that stressed caregivers of individuals with dementia are themselves more likely to develop dementia (Norton et al., 2010), there is increasing interest in the association between stressful life experiences and the risk of dementia. Recent studies have identified stress as a potential risk factor for dementia (Tsolaki, Kounti & Karamavrou, 2009; Johansson et al., 2010). Studies in this area are still nascent, but a key early finding is that stress in question needs to be significant or 'long standing' (Johansson et al., 2010 p2223).

One of the more enduring forms of stress reaction is Post Traumatic Stress Disorder (PTSD). Many people recover from PTSD within a year, but for some individuals, particularly the sexual abused, war veterans and concentration camp survivors the symptoms can last for many years (Bremner et al., 1996; Yehuda et al., 2002; Golier et al., 2002; Kendall-Tackett, Williams & Finkelhor, 1993). PTSD has also piqued the interest of dementia researchers for some of the biological, neurological and demographic similarities between the conditions: both target and reduce the volume of the hippocampal region of the brain (Geuze, Vermetten &Bremner, 2005; Gurvitis et al., 1996); both impair memory and cognition; (Samuelson et al., 2009; Nestor, Fryer & Hodges, 2006) both are associated with raised glucocorticoids levels in the brain (Sapolsky, 1996; Manenschijn, van den Akker, Lamberts & van Rossum et al., 2008) both share similar gender profiles (Gao, Hendrie, Hall & Hui, 1998; Ditlevsen & Elklit 2012); both have the shared co-morbidities of depression and anxiety (Yaffe , Vittinghoff & Lindquist, 2010).

It is important to understand whether there is a relationship between the two conditions because the UK government emphasis on prevention, early intervention and early diagnosis and on living well with dementia means that the understanding of risk factors for the development of dementia and the improvements in the care of people living with dementia are key priorities for research. The National Dementia Strategy was launched in 2009 with a view to improve awareness of dementia, achieve higher rates of early diagnosis and higher quality treatment for people with dementia. In order to further develop the work, the Dementia Challenge was launched in 2012 by Prime Minister David Cameron, highlighting the pressing need to meet the various challenges that dementia presents. Beyond the United Kingdom, dementia is a priority globally, with the Word Health Organisation (WHO) declaring it a public health priority and calling dementia a significant public health challenge (WHO & Alzheimer's Disease International, 2012). Developing an understanding of risk factors for dementia is crucial in the task of establishing protective factors to mitigate a growing problem worldwide.

Despite the known effects of PTSD on memory and cognitive tasks in older people and on accelerating the ageing process (Golier et al., 2002), screening for PTSD is not performed for people referred to memory clinics, whereas screening for conditions with possibly comparable effects such as traumatic brain injury, depression and anxiety is routinely undertaken. Shedding light on the nature, if any, of the association will go some way to support clinicians effectively diagnose dementia. Routinely asking about past/current PTSD as an indicator of risk for developing dementia, especially for certain populations (e.g victims of war, sexual abuse and armed forces personnel) could form part of the initial screening undertaken in memory clinics. Further, health professionals could be vigilant for the development of dementia in these vulnerable groups much earlier in life prior to the development of symptoms of dementia. Similarly, reviewing people diagnosed with the dementia for the [re]emergence of PTSD could help improve the care of people living with dementia.

This is the only review, to my knowledge, that specifically reviews the literature for an association between PTSD and dementia.The studies in this review are grouped as those which look at PTSD as a risk factor for the development of dementia and studies that examine PTSD in people with established dementia, with the consideration of the third factor,

that is, underlying shared risk factors existing for both conditions in the discussion and conclusion sections.

Objectives

The aim of this review is to critically evaluate the evidence regarding the association between PTSD and dementia and to contribute to the development of an evidence-based account of the association between PTSD and dementia.

Method

Search Strategies

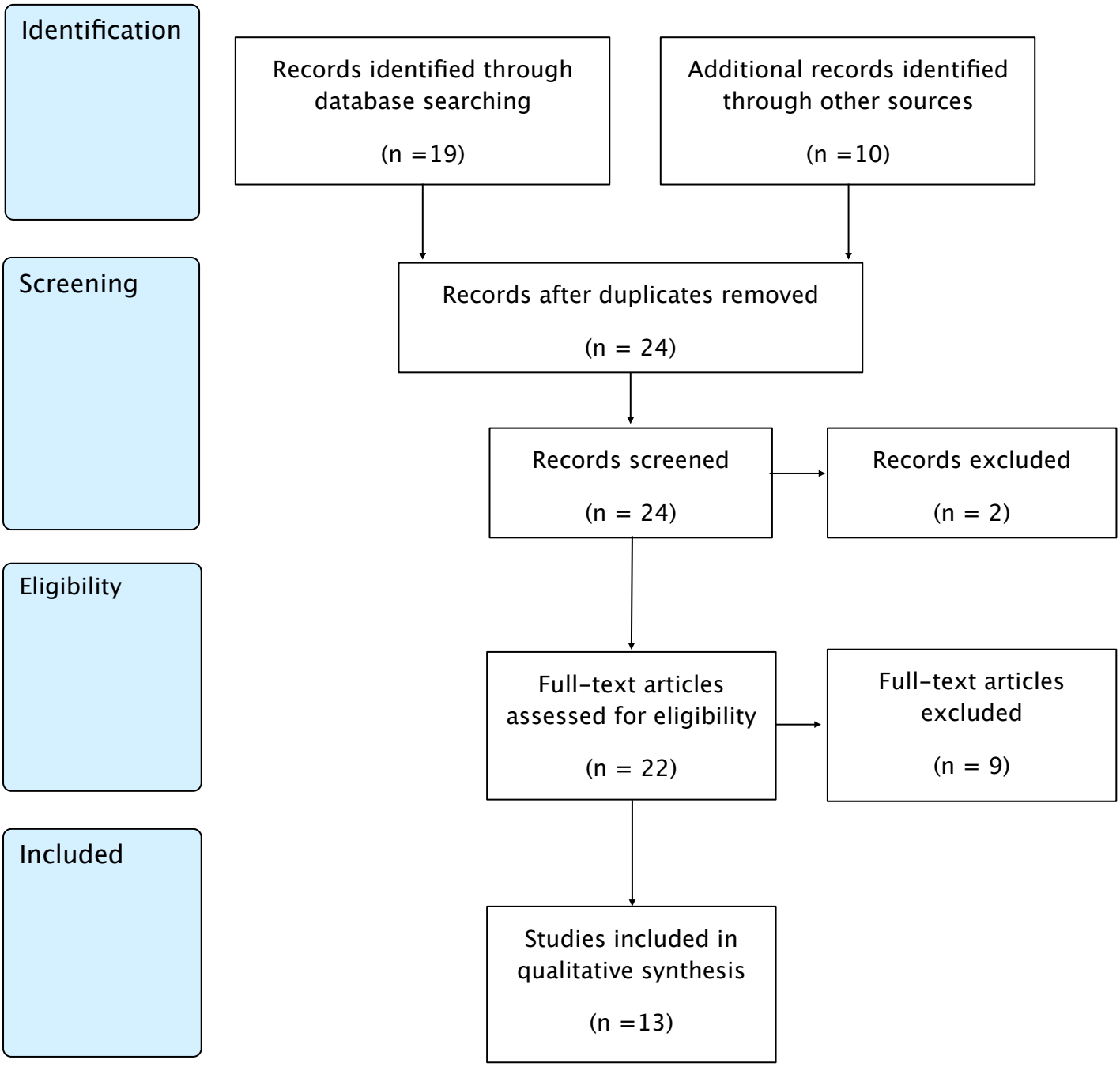
In order to identify relevant research articles, a number of databases were searched on June 23rd 2014, including PsychInfo, Ovid MEDLINE ® In-Process & Other Non-indexed Citations and Ovid MEDLINE ® and Embase Classic and Embase: Excertpt Medica (Ovid). The search was limited to peer reviewed journals and English articles. A keyword search that included the following words was carried out.

Table 1.1: Search Strategies and Exclusion Criteria

	Key words	**Search results**	**Exclusion Criteria**
1	Post traumatic stress disorder	29 929	
2	PTSD	48 947	
3	1 or 2	78 876	
4	Dementia	238 461	
5	Alzheimer*	278 790	
6	4 or 5	512 253	
7	3 and 6	19	
		14	Remove duplicates
		12	Nothing to do with PTSD or Dementia
		9	Article focus on neurological similarities of dementia and PTSD
		7	Editorials
		3	Participants did not have a diagnosis of a dementia
		3	**Remaining articles**
		5	**Search references for additional articles**
		5	**Additional hand search for relevant articles**
		13	**Total articles**

Results

Search Results



Once the article search had been restricted to those that were in English and peer reviewed, the key word search was completed (steps 1-7 in Table 1.1). The search retrieved 19 articles. Duplicates were removed and then abstracts were scrutinised to exclude articles not investigating the PTSD-dementia association; articles where participants did not have a diagnosis of dementia and PTSD, and articles that were primarily or exclusively focused on neurological similarities. Following this process, a hand search of the reference list of the articles obtained through the electronic search identified nine additional suitable articles. The 13 articles identified are categorised into two sets (i. PTSD after the onset of dementia and ii. PTSD leading to dementia) and presented in chronological order within each section. The first group consists of those articles considering PTSD as a risk factor for developing dementia in later life. The second group contains the remaining articles looking at the [re] emergence of PTSD in dementia.

The articles which met the inclusion criteria were mostly either quantitative studies or case studies. Therefore, in order to critically evaluate the journal articles in this review, two different quality criteria frameworks were used. The first framework was employed to evaluate the quality of the quantitative studies. For this purpose a framework designed by Caldwell et al. (2005) was used. For the case studies, a quality criteria framework specifically designed to assess case studies, namely Stake's checklist (2005), was used. Copies of both frameworks are provided in appendices A and B. See Table 2 for a summary of all the articles.

Table 2: Summary of articles

Title	Authors	Objectives	Design	Participants	Main Outcome Measures	Results	Conclusion
Trauma Reenactments in Aging Veterans with Dementia *(2013)*	Dallam, Mellman, Bhatnagar, Nguyen & Kurukumbi	To understand the nature of the trauma memories that are triggered in veterans with dementia and its association with dementia subtypes.	Between group design retrospective case note analysis.	All participants had dementia. In the control (n=32) only 2 had a previous diagnosis of PTSD but no current symptoms. Of the experimental group (n=16) all had a pervious diagnosis of PTSD and all exhibited recurrent PTSD symptoms	Incidence of dementia subtypes and caregiver report of recurrent PTSD symptoms.	The subtypes of dementia differed between the two groups with the experimental group having a higher rate of Lewy body dementia and Parkinson's dementia. The control group had higher rates of Alzheimer's, Vascual and Mixed. An increased association of sleep related episodes and subcortical dementias were found.	Authors suggest Rapid eye movement behavior disorder (RBD), as a model for understanding the link between Dementia and reactivated PTSD.
Posttraumatic Stress Disorder in Holocaust Survivors *(2011)*	Sperling, Kreil, & Biermann	To investigate whether Holocaust survivors with PTSD are at risk of developing dementia	Within group study using retrospective case note analysis.	93 Holocaust victims (49 men, 43 women) from Israel, United States, Canada and Argentina born between 1911 and 1943. All of whom had a diagnosis of PTSD and 70% had PTSD+ with GAD and 50.5% had major depression and 17% abused substances.	DSM-III-R, DSM_IV, ICD-9 and ICD-10 were used to categorise diagnoses. Kruskal-Wallis test and Mann-Whitney U to make somatic diagnosis.	16% were found to have dementia based on ICD-10. 60% had Vascular Dementia, 20% had Alzheimer's Disease and the remaining 20% had other subtypes of dementia.	A high incidence of dementia
Greater Prevalence and Incidences of Dementia in Older Veterans with Posttraumatic Stress Disorder *(2010)*	Qureshi, Kimbrell, Pyne, Magruder, Hudson, Pharm, Petersen, Yu, Schulz & Kunik	To investigate the relationship between PTSD and dementia in older veterans	Administrated database study.	Veterans aged 65 and older who received a Purple Heart or had a diagnosis of PTSD and a control of veterans the same age who did not have a diagnosis of PTSD nor were recipients of a Purple Heart.	Incidence of dementia after controlling for confounding factors using a multivariate logistic regression.	Veterans with PTSD and no Purple Heart had a significantly higher incident rate of dementia when compared to those without PTSD and those without a Purple Heart. Those with PTSD and no Purple Heart were twice as likely to have a diagnosis of dementia then those with only a Purple Heart or those without both PTSD and a Purple Heart.	Veterans with PTSD have a higher incidence of dementia.

Title	Authors	Objectives	Design	Participants	Main Outcome Measures	Results	Conclusion
Severely stressful events and dementia: A study of an elderly Greek demented population *(2009)*	Tsolaki, Papaliagkas, Kounti, Messini, Boziki, Anogianakis, & Vlaikidis	To investigate the relationship between stressful events and cognitive impairment of older adults.	Longitudinal (7 year) between group design study.	1271(500 male and 771 female) individuals with a diagnosis of dementia according to the DSM-IV criteria and a control of 140 individuals without any cognitive impairment who were matched by age and gender.	Mini-Mental Status Examination (MMSE), the Cambridge Cognitive Examination (CAMCOG), the Functional Rating Scale for Symptoms of Dementia (FRSSD), the Functional-Cognitive Assessment Scale (FUCAS), the Geriatric Depression Scale (GDS), and the Hamilton Rating Scale for Depression	990 (77.9%) reported experiencing stressful events before the onset of dementia. Only 281 (22.1%) reported an insidious onset to their dementia. Of the control a significantly smaller number experienced stressful life events (55%).	Stressful events in later life can lead to a cognitive decline.
Posttraumatic Stress Disorder and Risk of Dementia Among US Veterans *(2003)*	Yaffe, Vittinghoff, Lindquist, Barnes, Conisky, Neylan, Kluse & Marmar	To investigate if PTSD is a risk factor for developing dementia among older US veterans	Stratified retrospective cohort study	181 093 veterans who were 55 years or older without a diagnosis of dementia from fiscal year 1997 to 2000 (53 155 veterans with PTSD and 127 938 without PTSD)	International Classification of Disease, Ninth Revision, Clinical Modification codes.	Veterans with PTSD had 7 year cumulative incident dementia rate of 10.6%, those without PTSD had a rate of 6.6% ($P<0.001$).	Those diagnosed with PTSD were at a nearly 2 fold higher risk of developing dementia compared with those without PTSD.

Title	Authors	Objectives	Design	Participants	Main Outcome Measures	Results	Conclusion
Prolonged Exposure Therapy for a Vietnam Veteran With PTSD and Early-Stage Dementia *(2013)*	Duax, Waldron-Perrine, Rauch & Adams	To demonstrate the successful use of prolonged exposure therapy with a veteran with PTSD and early stage dementia	Single case design	65 year old Vietnam Veteran	The Mini Mental Status Examination (MMSE), Wechsler Abbreviated Scale of Intelligence (WASI), Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), The Trail MakingTest Parts A & B, Boston Naming Test, Number Information Test, Mini-mult a shortened form of the MMPI-2 and the Geriatric Depression Scale(GDS) Mini International Neuropsychiatric Interview 6.0 (MINI), Clinician-Administered PTSD Scale for DSM-IV (CAPS) and PTSD Checklist–Civilian Version (PCL-C)	PTSD and depression symptoms reduced with the use of prolonged exposure therapy and cognitive functions improved as a result of the reduced psychiatric symptoms.	Prolonged Exposure Therapy was effective in reducing PTSD symptoms. This is beneficial as it allows for a clearer assessment of cognitive ability and it can improve quality of life for those with both PTSD and dementia.

Title	Authors	Objectives	Design	Participants	Main Outcome Measures	Results	Conclusion
War-Related Somatoform Disorder in an Older Adult Veteran *(2012)*	Jacobs & Dinoff	To present a case study of a veteran who lived in nursing home and for whom a successful treatment program that included CBT, ACT and Montessori-based techniques was created.	Case study	90 year old WWII veteran with multiple psychiatric diagnoses: undifferentiated somatization disorder, anxiety, depression, and Vascular Dementia. He was also thought to have had PTSD in the past but did not have a formal diagnosis in his notes.	Minnesota Multiphasic Personality Inventory–2 (MMPI-2) (in the past), Saint Louis University Mental Status Examination (SLUMS), Geriatric Depression Scale (GDS) and a modified ACT Valued Living Questionnaire	Scores improved on both the SLUMS and GDS post intervention. His anxiety about being in the nursing home reduced, he was less anxious when his wife left after a visit and he caused less disruption to nursing staff with regards to his health issues.	Multidiciplinary working is required when working in a nursing home setting with older adults presenting with complex needs. Some adaptation may also need to be made to psychological treatments to be made effective for older adults with dementia
A strange case of Comorbidity in a 60-year-old Portuguese war veteran: War Post Traumatic Stress Disorder, Early Fronto-Temporal Cerebral Atrophy, and Strong Neuropsychological Symptomatology. A Neuropsychological Review *(2007)*	Maia, da Silva, Bartolomé, Correia, & Parrilla	The present a case study of a 60 year old veteran with PTSD and Dementia	Case Study	60 year old veteran with PTSD and Frontal Temporal Dementia	Mini Mental Status Examination (MMSE), Portuguese Experimental Version of Luria Nebraska Neuropsychological Battery The verbal learning test Complex Figure Paced Auditory Serial Addition Test (PASAT) Luria Graphical Series CAT scan	PTSD symptoms were present for 40 years but worsened during the last 2-3 years. CAT scan showed atrophy in the polar frontal regions of the brain as well as gernalised widening of the cortical ridges.	Communication between the hippocampus and the amygdala seem to be mediated by the prefrontal medial cortex. It also acts as a modulator of stimulus reaction. The pre-frontal dysfunction seen in this older adult appears to exacerbate his psychiatric difficulties.

Title	Authors	Objectives	Design	Participants	Main Outcome Measures	Results	Conclusion
Emergence of PTSD in Trauma Survivors with Dementia *(2001)*	van Achterberg, Rohrbaugh & Southwick	To describe 3 case studies of individuals who experienced an exacerbation of their PTSD symptoms after the onset of Dementia.	Case Series	3 individuals (1 male and 2 females) with a diagnosis of dementia and had experienced traumatic events earlier in their lives however none of whom suffered from PTSD symptoms in the past. One survived the sinking of the Titianic, one was a WWII veteran and the last was a survivor of the Holocaust.	DSM-IV	PTSD symptoms worsened with onset of dementia in all 3 individuals, daytime intrusive memories increased for all 3. Flashbacks were experienced by 2. Increased agitation and irritability was noticed in all 3.	Findings are suggestive of increase in PTSD symptoms with the decline of cognitive function.
Worsening of Post-Traumatic Stress Disorder Symptoms with Cognitive Decline: Case Series *(2001)*	Mittal, Torres, Abashidze & Jimerson	To present 3 cases of individuals with post-traumatic stress disorder (PTSD) symptoms which are associated with cognitive decline	Case Series	3 individuals with a history of PTSD which was reasonably under control however the onset of Alzheimer's disease, Vascular dementia or alcohol-related dementia triggered and exacerbated their PTSD symptoms.	Mental status examination, neurological testing and brain MRI	All 3 showed an increase in PTSD symptoms after the onset of their dementia	The cases presented show that PTSD symptoms may be exacerbated by dementia
A series of cases of dementia presenting with PTSD symptoms in World War II combat veterans *(2000)*	Johnston	To present 3 cases of individuals with no prior history of PTSD demonstrated PTSD symptoms at the onset of dementia	Case series	3 men aged 68,77 and 78 who were either WWII or Korean combat veterans.	Mini Mental Status Examination (MMSE)	Onset of dementia was accompanied by PTSD symptoms. All families did not seek help even though cognitive decline was apparent until after displays of violence.	Onset of dementia may trigger PTSD symptoms in individuals who did not previously show PTSD symptoms earlier in life.
Persistence of combat-related posttraumatic stress symptoms for 75 years *(1998)*	Hamilton & Workman	To investigate the duration of PTSD symptoms and in a WWI combat veteran	Case study	75 year old WWI combat veteran with PTSD		PTSD symptoms persisted in this individual for 75 year and increase in later life with onset of dementia and hospitalization.	PTSD symptoms may persist for a prolonged period of time and may be affected by the aging process.
Sexual Violence, PTSD and Dementia *(1997)*	McCartney & Severson	Case study about 82 year old women with Alzheimer's disease and PTSD after a sexual assault	Case study	82 year old female with Alzheimer's disease and PTSD	Cognitive Capacity Screening Exam	Responded to 25 mgs of sertraline which was raised to 50 mgs after a week	PTSD needs to be diagnosed properly in older adults in order for it to be treated properly

Description of the Studies

The aim of this section is to examine the extent to which i) a diagnosis of dementia triggers or worsens PTSD symptoms ii) a diagnosis of PTSD increases an individual's risk of developing dementia. Consideration will also be given to the variability if any amongst the studies in this area as well as the methodological limitations or other threats to the validity of the findings.

PTSD after the Onset of Dementia

Introduction

The research reviewed in this section consists of six case series, two case studies, one single case design and a retrospective case note analysis study using a between group design. Most of the studies are not based in the UK. All these papers document the onset of dementia coinciding with the triggering or worsening of PTSD symptoms. The majority of studies in this section were case series, and the number of participants in each study is generally quite low, ranging from one to three. The studies were typically inspired by clinicians encountering a small cluster of presentations in clinical settings that warranted documenting or further study. The social-cultural setting of the studies is that the subjects in these studies are often veterans (ranging from WWI to Vietnam), holocaust survivors and a case relating to a Titanic survivor. A consideration of the quality scores in Appendix A reveals that in general the level of rigour in these studies met most of the standards expected of good quality case studies.

Research articles

In this section we will provide a short summary of each study alongside a critique and a statement of the main findings.

Using single case design Daux, Waldron, Perrine, Rauch and Adams (2013) look at the effectiveness of prolonged exposure therapy (PET) for PTSD symptoms of a 65 year old Air Force veteran in the United States. This veteran was also being assessed for dementia. The introduction includes a brief meditation on late onset PTSD with a succinct presentation of various hypotheses on this phenomenon followed by equally brief discussion of the relationship between PTSD and dementia. The authors conclude that PTSD may be a 'common co-occurrence' with dementia. The next section involves an outline of clinical and

personal history, following which the authors present the pre-intervention measures, the steps involved in the treatment and the post-intervention evaluation. The discussion section is mainly given over to the extent to which PTSD symptoms were reduced in the individual with dementia. The factors which contributed to the successful treatment are explored. Of particular interest is that the differential diagnosis of Alzheimer's type dementia was easier to establish after the treatment of co-morbid PTSD and depression. The earlier diagnosis had been inconclusive.

Jacobs and Dinoff (2012) describe a case study of a World War II (WWII) veteran with a unique somatic presentation of PTSD which worsened after a diagnosis of vascular dementia. Although the patient had chronic somatic 'probable' PTSD, i.e the PTSD predated the onset of dementia, the authors suggest that when the dementia 'damaged' his brain, it curtailed 'his ability to process his deepest fears'. The relationship between PSTD and dementia is very briefly discussed in the theoretical and research basis for treatment (only one previous study is referred to), as the authors are more interested in the hypothesised somatic nature of the PTSD, which they propose is a variant of PTSD. Very little time is given to consideration as to why the probable somatic PTSD symptoms worsened after the onset of vascular dementia and general and vague language is used to describe the possible pathway.

Reviewing the records of patients of a geriatric medicine clinic, Dallam, Mellman, Bhatnagar, Nguyen and Kurukumbi (2011) aimed to characterise the development of PTSD in veterans with dementia, and, significantly, to look at the relationship between PTSD and dementia subtypes. The authors compared two groups of veterans with dementia. The control group (n=32) did not have any current PTSD symptoms and only two had a previous diagnosis of PTSD. The second group (n=16) all had a previous diagnosis of PTSD and current symptoms. Looking at the type of dementia the individuals had, the authors report a significant difference between the two groups, those with re-enacted PTSD being diagnosed more with sub-cortical types of dementia. They also found that most PTSD symptoms in veterans with dementia occurred at night. There is some lack of clarity regarding the study's design and results, which is most probably due to the fact that the findings are reported in a letter to an editor in a journal where word count is very limited. There are also some oddities. It is not clear why two veterans with PTSD diagnosis were admitted to the control group.

Given that a key aim of the study was to evaluate PTSD relationship with dementia subtypes, it reduces the extent to which the dementias of veterans with PTSD can be compared to the control group. There are also limitations on the generalisability of the findings given the small sample size, which the authors themselves acknowledge.

Originally written in Portuguese, this somewhat poorly translated neurological case study details the case of a 60-year old Portuguese war veteran. (Maia, da Silva, Bartolome, Correia & Parrilla, 2007). The case history, neuropsychological test performance and CAT scans of the patient are presented. Based on the test results and CAT scans, fronto-temporal dementia is diagnosed. The discussion, inter alia, considers the impact of PTSD on the brain atrophy noted in the patient. Citing evidence in the literature, they note that prolonged arousal of the amygdala in PTSD can lead to dysfunction in inhibiting memories. They go on to note in general that prolonged stress can lead to neurodegenerative diseases. As mentioned, this originally Portuguese article is let down somewhat by its translator and it is difficult, at times, to follow all the arguments being made. However, the authors appear to implicate amygdala disregulation as the cause of PTSD in the dementia patient in their conclusion, commenting that the prefrontal medial cortex mediates between the amygdala and the hippocampus.

In a case series Mittal, Torres, Abashidze and Jimerson (2001) describe three clients ranging in age from 57 to 70 in whom war-related PTSD worsened with the onset of dementia. They found indications that the onset of dementia either triggered or exacerbated PTSD symptoms. Using MRI scans, clinical interviewing and neuropsychological tests (WAIS, clock drawing, trails MMSE, verbal learning test) neurobiological and psychological explanations are put forward by the authors for the worsening of PTSD symptoms in dementia. They suggest that the deterioration of neural pathways in dementia may led to a reduced capacity to inhibit emotional memories and further that dementia's impact on short-term memory may move older memories to the foreground.

Van Achterberg, Rohrbaugh and Southwick (2001) present three cases in which PSTD symptoms increased after the onset of dementia. Two of the cases relate to non-combat PTSD, with one individual having survived the sinking of the Titanic and the other being a Holocaust survivor. The third individual was a WWII veteran. After detailing the three cases, Achterberg et al. (2001) suggest that traumatic memories may be more resistant due to the

way they are encoded. They mention the effect of dementias on short term memory in comparison to long term memory as well as hippocampal reduction in both conditions. They also suggest by way of explanation that the usual coping strategies such as avoidance may be disrupted by dementia.

Reporting the case of an 82-year old women with Alzheimer's disease who developed PTSD after sexual abuse in a care home, McCartney and Severson (1997) discuss the details of the sexual assault and the psychological consequences for the victim. The treatment course is outlined as well as the extent to which it was effective. PTSD symptoms waned after three weeks in the case after treatment with 50 mgs sertraline. Following this, the authors discuss the difficulties inherent in diagnosing PTSD in older adults in general and those living with dementia in particular. The presentation of PTSD in older adults with cognitive impairments in discussed. However the specific interaction of PTSD and dementia is not explored in the article.

Johnston (2000) presents a series of three cases of combat veterans with dementia presenting with PTSD, with their ages ranging from 68-78. The participants were veterans of the Korean war and WWII. In all three cases there was a diagnosis of dementia or suspected dementia when they presented for treatment for their PTSD. All the subjects were able to either manage their PTSD symptoms or were asymptomatic until they experienced dementia. After describing the particular experiences, Johnson presents a series of possible implications of his findings which she suggests warrant further investigation: the prevalence of co-morbid PTSD and dementia, as well as whether there is an association between one of the dementias and PTSD; the impact of PTSD on the progression of dementia and on dementia care; neurological and psychosocial connections between the two conditions and the way in which veterans respond to traumatic experiences.

Reporting the case of Mr A, a 94-year old World War 1 survivor, Hamilton and Workman (1998) detail PTSD symptoms that worsened after a diagnosis of Alzheimer’s disease. Describing the single case in detail, the authors then offer plausible interpretations for the worsening of PTSD symptoms: decrease in inhibition of emotionally charged memories as well as the health difficulties of Mr A. Although the relationship between PSTD and dementia is of interest to the authors and discussed, the primary interest in the persistence

of PTSD over the lifespan. That is, the emphasis appears to be on in the fact that the symptoms lasted for 75 years. Indeed the authors remark that 'the present case demonstrates the remarkable persistence of post traumatic stress disorder.' (Hamilton & Workman, 1998; 763-764)

The nine studies reviewed above all considered whether development of dementia can trigger or worsen PTSD symptoms. Most of the research in this area is in the form of case studies/series, which are generally recognised to be at the lower end of high quality health care research. Most of the participants in the studies were veterans. Given that research in this area is still in its early stages, we can expect to see more robust, and hopefully some controlled studies in the near future to take this research forward. There will be a comparison and contrasting of these studies in the discussion section. We can see from the quality scores in the tables in the appendix A that the case series/studies measure well against the standards set for case studies. However, the amount of confidence we can invest in the thesis that the development of dementia can trigger or worsen PTSD symptoms is limited due to the lack of more robust high quality research supporting this thesis.

PTSD as a risk factor for dementia

The research reviewed in this group consists of four retrospective studies that all considered whether PTSD is a risk factor for the development of dementia. The number of people in the studies was often quite large, ranging from 93-200,000. The study period was often also considerable, ranging from 7-9 years in three of the longitudinal studies (the Sperling, 2011 study does not report study length). In terms of the cultural setting of the studies, most are U.S based, and the subjects in three of the studies are veterans, whereas in one study the participants are holocaust survivors. Given the nature of the studies, all participants are older adults. In the veteran studies there is a preponderance of male subjects. The range of quality scores in Appendix B shows that in general the level of rigour in these studies meets most of the standards expected of high quality quantitative research.

Sperling et al. (2011) examined the relationship between PTSD and dementia by undertaking research into holocaust survivors. Looking at the medical records of 93 holocaust survivors with PTSD, Sperling et al. (2011) found 14% or 16% (both figures reported) of the sample developed dementia. This study did not compare the survivors with PTSD who

developed dementia with a control group. It would have been useful to examine the proportion of survivors without a PTSD diagnosis that went on to develop dementia. The authors suggest that PTSD might accelerate the ageing process.

In their retrospective study of nearly 200,000 US veterans Yaffe et al. (2010) found veterans with PTSD were more than double as likely to develop dementia compared to those without PTSD. Adjusting for other variables, the risk remained at almost twice as likely. Looking out for the development of dementia over a seven year period, Yaffe et al. (2010) found an incident rate of 10.6 percent in veterans with PTSD compared to 6.6 percent in veterans without a diagnosis of PTSD. Using the cox proportional hazard models the authors found a hazard ratio of 2.31, which dropped to 1.77 after multivariable adjustment. The authors suggest screening for cognitive impairment for people with PTSD.

Tsolaki et al. (2010) found that people with a dementia diagnosis were twice as likely to have been exposed to traumatic experiences (n= 1290) compared to a control group of participants who were not cognitively impaired (n= 140). It is not clear that the evidence is strong enough to establish a causal relationship. Moreover stressful events and PTSD are seen as the same thing by author. A weakness of the study is their reliance on subjects to recall past stressful incidences. The authors acknowledge that the health difficulties reported by participants may have skewed the results as the diseases and surgical procedures patients were exposed to may carry risk for the development of dementia.

In their retrospective study of over 10,000 male veterans, Qureshi et al. (2010) report greater incidence and prevalence of dementia for veterans with PTSD compared to veterans without PTSD. After controlling for variables, the authors found that veterans with PTSD were twice as likely to develop dementia. Qureshi et al. (2010) found a dementia period prevalence risk, over the eleven year course of the study, of between 7.2 -11.1 for veterans with PTSD and an incident risk of between 6.8 - 9.5. However key confounders such as intelligence and education were not controlled for, which the authors recognise as a limitation of the study.

The four retrospective studies reviewed above all considered whether PTSD is a risk factor for the development of dementia. The research in this field has been largely carried out with veterans and holocaust survivors. There will be a comparison and contrasting of this set

of studies in the discussion section. However we can say with some confidence that the range of quality scores in the table above as well as the research findings point firmly to the existence of a positive association in this direction.

Discussion

In this section we consider in turn the results of studies which looked at the re-emergence of PTSD in Dementia and studies that looked at PTSD as a risk factor for dementia.

PTSD after the onset of Dementia

In total twenty-eight case studies of people with dementia in whom PTSD occurred, reoccurred or worsened were reported across nine studies. The participants in these studies were mostly veterans, although findings from a holocaust survivor and a Titanic survivor are also reported. Researchers described dramatic changes in PTSD symptoms after the onset of dementia as well as cases in which PTSD symptoms were reported for the first time after the onset of dementia. One study characterised most symptoms for this population occurring at night (Dallam et al., 2011).

In order to evaluate the presentation of PTSD in people with dementia, it is necessary to consider the trajectory of PTSD. PTSD usually occurs within one month of the traumatic experience but can be delayed in around 15% of people by months or years (McNally, 2003). For most people recovery from PTSD, even without treatment, is within the year (Breslau, Davis, Anderski & Peterson, 1991; Kessler, Sonnega, Bromet, Hughes & Nelson, 1995). However, for a significant minority (30%) the duration of symptoms can be for three years or more (Kessler et al., 1995). There is also evidence of symptoms lasting many years, particularly for veterans (Kidson, Douglas, & Holwill, 1993; Lee, Vaillant, Torrey, & Elder, 1995; Bremner et al., 1996). It is noteworthy that PTSD symptoms should resurface after the onset of dementia in light of evidence from longitudinal studies that the psychological impact of traumatic experiences subsides with age (Tennant, Fairley, Dent, Sulway & Broe, 1997).

Methodological considerations

The methodological weakness of the research in this area affects the extent to which solid conclusions can be made. Most of the studies looking at PTSD after the onset of

dementia were case studies, which are recognised as being less robust than other research design methods. Case studies are limited in the extent to which they are generalizable to the larger population (Crowe et al., 2011). They are also quite susceptible to interpreter bias. Given that the case studies in question were all retrospective in nature, there is the additional danger of bias due to recall (Sackett, 1979). Although there is some suggestion that multiple case studies can be considered on equal terms as multiple experiments (Yin, 1999), there is need to go beyond a naturalistic understanding of the topic before any firm conclusions can be drawn. Some of the researchers themselves have recognised the paucity of the evidence gathered thus far, calling for further studies (Johnston 2000).

The literature also suffers from a lack of clarity as to what the research aims in the field are and the somewhat confusing different terminology employed by researchers. Most of the existing data refers to the 're-enactment' of PTSD with the onset of dementia, thereby ruling out causality, as a key criteria to establishing causality is that the cause (dementia) must predate the outcome (PTSD). However there is some data examining 'delayed onset' which does not preclude causality. With such language it is not easy to establish the chronology of events or to understand if we are referring to the same thing. Given that there is evidence that Alzheimer's disease related changes in the brain begin 20-30 years prior to its onset, there are suggestions that these brain changes related to incipient dementia could make an individual more vulnerable to stress (Johansson, 2010) and hence to development of PTSD.

In addition to the complications caused by terminology, there are difficulties inherent in the identification or diagnosis of PTSD. This is an area that requires close attention. Delayed onset PTSD is considered uncommon (McNally & Richard, 2003). However, re-enacted PTSD is considered to be quite common (Frueh, Grubaugh, Yeager & Magruder, 2009). Port et al. (2001) distinguish between re-enacted and delayed onset PTSD, citing the former as more common. It also suggested that prior to the occurrence of Delayed Onset PTSD, 'sub-threshold' symptoms of PTSD are experienced. The difference between a delayed onset following sub threshold symptoms and re-enacted PTSD is not one that can bear much weight and is at risk of collapsing. In order to obtain clarity regarding the association between PTSD and dementia, future studies would have to untangle these two types of PTSD which are sometimes not properly distinguished. In order to further the thesis

that dementia triggers PTSD, researchers need to be able to demonstrate that (i) re-enacted PTSD is elevated amongst veterans with dementia when compared to veterans without dementia and (ii) delayed onset PTSD is higher in the older adult population with dementia than those without dementia

Explanations put forward for the association

Several biological, social and psychological explanations are put forward in the literature for why PTSD might be likely to emerge or reemerge in those with dementia (See table 3). One explanation is that cognitive decline associated with dementia reduces the ability of a person to engage cognitive defence mechanisms such as avoidance (Floyd, Rice & Black, 2002). An explanation that draws on social causes of PTSD in dementia is that older adults are likely to have retired and are thus less likely to be occupied with work, which will allow for more time to focus on unwanted thoughts (Op den Velde et al, 1990; Ruzich, Looi & Robertson, 2005). Various losses experienced in later life may mean that symptoms are more likely: the loss of social support (Hiskey, Luckie, Davies & Brewin, 2008); the loss of loved ones (Charles et al 2006) or the loss of physical independence (Macleod 1994). Whereas psychodynamic perspectives revolve around the awakening of repression memories (Ladson & Bienenfeld, 2007) Biologically, it has been argued that traumatic memories are more immune to cognitive impairments due to the way in which they are encoded as well as that cell loss and atrophy caused by dementia disinhibit emotional memories (Mittal 2001). This paradox perhaps needs clarifying: either traumatic memories are less easily dislodged by impairment or more easily dislodged.

Table 3: Possible mechanisms for relationship between PTSD and dementia

Research Article	Proposed possible Mechanisms	Evidence for proposed mechanism (if any)	Counter evidence (if any)
Yaffe et al (2010)	PTSD triggers a process of neurodegeration through frontal lobe loss and dysfunction.	1. Shin Rauch & Pitmsn (2006)- PTSD triggers medial prefrontal cotex dysfunction. As bloodflow in prefrontal decreased, bloodflow in amygdala increases 2. Samuelson et al (2009) PTSD triggers a process of hyperarousal which wears down the pre-frontal cortex eventually leading to dysfunction in tasks such as facial recognition and working memory	2. If true & hyper arousal leads to a wearing down of the pre-frontal cortex, there should be worse memory performance the older the truama- no such evidence appears available
Duax, Waldron, Perrine, Rauch & Adams (2013)	n/a	n/a	n/a
Jacobs & Dinoff (2012)	n/a	n/a	n/a
Maia, da Silva Bartolome, Correia & Parrilla (2007)	Acute and reccurent stress can trigger neurodegeneration	Johansson et al 2010 (i)Prolonged stress leads to hypertension which leads to Alzheimer's and vascular dementia (i)Stress raises the level of pro-inflammatory cytokines leading to Alzheimer's disease (iii)Prolonged stress leads to cardiovascular disease which leads to dementia	
van Achterberg Rohrbaugh & Southwick (2001)	Dementia disrupts negatively affected previously adequate coping strategies leading to PTSD symptoms	Floyd, Rice & Black (2002)	
Dallam, Mellman, Bhatnager, Nguyen & Kurukumbi (2011)	Rapid Eye Movement	Boeve B.F., Silber M.H., Parisi J.E. et al. (2003) -Evidence that Parkinson's disease and Lewy body dementia may be associated with Rapid Eye movement disorder	
Mittal, Torres, Abashidze& Jimerson (2001)	1. Dementia damages neural pathways leading to a reduced capacity to inhibit emotional memories 2. Disruption of the hypothalamic-pituitary axis (i.e stress hormones)		2. Little evidence of hyposecretion of GCs in PTSD (Sapolsky 2000)
McCartney and Severson (1997)	n/a	n/a	n/a
Johnston (2000)	n/a	n/a	n/a
Hamilton and Workman (1998)	Life stage developmental: tasks of ageing such as a need to find meaning in older age, mourning negatively affect previously adequate coping strategies	Op den Velde et al (1990) Hiskey Luckie, Davis & Brewin (2008)	

Research Article	Proposed possible Mechanisms	Evidence for proposed mechanism (if any)	Counter evidence (if any)
Tsolaksi et al (2010)	Stressful life events lead to depression which leads to overactivity of the hypothalamic– pituitary–adrenal axis and hypercortisolaimia which predisposes to dementia	Fountoulakis, K.N., Kaprinis, S.G., Iacovides, A., Phokas, K., Kaprinis, G., (2005)	Link between stressful life events and depression is doubtful Paykel, E., (1994).
Qureshi et al (2010)	1. PTSD leads to reduction in cognitive reserve which predisposes to dementia 2. hippocampal dysfunction and smaller volume in PTSD is risk factor for dementia		1. low cognitive reserve may be risk factor for both ptsd and dementia 2. small hippocampal volume could be a risk factor for PTSD rather than an outcome of it (Gilbertson et al 2002)
Sperling et al 2011	PTSD accelerates the ageing process	Golier JA, Yehuda R, Lupien SJ, Harvey PD, Grossman R, Elkin A (2002)	dementia is not considered a part of the ageing process

Much of the emphasis in the literature is on traumatic events in the distant past. However it is worth considering whether the trauma and the response to it being observed in the clinical population is new (see Table 4 for possible pathways of association). Studies investigating the co-occurrence of PTSD and psychosis have explored the extent to which the onset of psychosis and its treatment is traumatic, implying that psychosis (and associated treatment) precipitates PTSD. (Morrison, Frame & Larkin, 2003). It is possible that the experience of dementia and the treatment is traumatising. There is evidence to suggest that hospitalisation for older adults can be traumatic as well as evidence pointing to the abuse of people with dementia by carers (Coyne, Reichman & Berbig, 1993) and by patients and staff in care settings (Pillemer & Bachman-Prehn, 1991; Wilson 1994). It is possible therefore that the PTSD we see in individuals with dementia is not long-standing but rather more recent. This would be in line with research demonstrating that most symptoms of PTSD occur within the first month after the traumatic experience (McNally & Richard 2003). Even if it not a recent trauma, it is possible that hospitalisation can trigger the revival of PTSD with evidence suggesting that hospitalisation can worsen PTSD (Hamner, 1994). That said there is also evidence that patients with dementia do not find its onset stressful (Tsolaki et al., 2011). An exploration of the type of memories/disturbances experienced in PTSD after dementia show that it is often old traumatic memories, which might be being re-stimulated by new environments or circumstances. Given the different possible interactions of trauma, PTSD and dementia, various pathways are demonstrated in table 4.

Table 4: The Pathway of Association

The Pathway of Association				
TRAUMA	→	PTSD	→	DEMENTIA
TRAUMA	→	DEMENTIA	→	PTSD
DEMENTIA	→	TRAUMA	→	PTSD

PTSD as a risk factor for Dementia

In total, four studies, focusing mostly on holocaust survivors and war veterans, looked at whether PTSD predisposes to dementia. The most significant of these studies are the Yaffe et al. (2010) and Qureshi et al. (2010) studies. Qureshi et al. (2010) found a dementia period prevalence risk of between 7.2 - 11.1 for veterans with PTSD and an incident risk of between 6.8-9.5.Yaffe et al. (2009) did not look at prevalence but reported a slightly higher dementia incident rate of 10.6 . The prevalence rates for dementia in the general population in the United States for similar age groups are between 2.1-6.8 (Prince et al 2013). The incident rates are for similar age groups are between 0.1 to 7.2 (Gao et al., 1998)

Overall, the results of these studies show an elevated risk of dementia for those with PTSD. The studies reinforce one another to establish a consistency in positive association. Yaffe et al. (2010) and Qureshi et al. (2010) do begin to establish evidence of a consistent directional association between PTSD and dementia: Both studies showed a significant strength of positive association, with individuals with a diagnosis of PTSD having an elevated risk of developing dementia 1 .77 (Yaffe et al., 2010) or ~ 2 (Querishi et al., 2010), both studies establish that the PTSD came before the onset of dementia. These studies clearly establish the direction of the association that the cause predates the outcome

Methodological concerns

While some of the studies reviewed controlled for variables such as depression anxiety and traumatic brain injury (TBI), which goes some way to establishing specificity, none of the studies consider whether veterans or holocaust survivors were exposed to chemicals or other substances which might be confounding or indeed be an underlying cause

of both conditions. Nonetheless, variability was controlled to a fair degree by Yaffe et al. (2010) and Qureshi et al. (2010), who adjusted for medical and neuropsychiatric co-morbidities as well as for demographic factors. Both studies found similar results even after they excluded participants with a clinical history of TBI, depression and substance misuse, which allows us to consider more specifically the effect of a PTSD diagnosis on the development of dementia.

All of the studies were retrospective, which are more susceptible to bias than prospective studies (Ward 1999). However, in their favour Yaffe et al. (2010) and Qureshi et al. (2010) did also collect new data and watch for the development of dementia in individuals with PTSD during the study period, which was a seven year period on average in the Yaffe et al. (2010) study and nine years in the Qureshi et al. (2010) study. Yaffe et al. (2010) found an incident rate for veterans with PTSD of 10.6 per cent compared to 6.6 per cent in veterans without a PTSD diagnosis. Qureshi et al. (2010) found an incident rate for veterans with PTSD of 9.5 per cent compared to between 4 to 5.6 per cent in the various comparison groups without a PTSD diagnosis. The preponderance of male participants in the veteran studies means that the results cannot be generalised to females, a fact attested to by the researchers themselves.

Explanations put forward for the association

Biological explanations of the thesis that PTSD predisposes to dementia have been spurred by the neurological similarities between the conditions. Tsolaki (2009) found similarities between Alzheimer's and PTSD, in three main areas: hippocampus, medial temporal lobe and cingulate, although brain scans of PTSD showed greater variation in its effects on structure and function across the brain than those of Alzheimer’s disease. (Phan et al. (2002) note that the neural pathway of traumatic recall traces the regions of the brain deteriorate in dementia. Citing these similarities, Mercer et al. (2010) suggest that PTSD triggers a process of neurodegeneration through the mechanism of increased glucocorticoids which eventually leads to the formation of neurotoxic beta amyloid found in AD. However, while there is evidence that high concentrations of glucocorticoids can have a neurotoxic effect (Chen et al., 2002), there is little evidence of hyposecretion of glucocorticoids in PTSD (Sapolsky, 2000). Sapolsky looked at whether the stress steroids were a contributing factor to

hippocampal reduction and concluded that in the absence of the hyposecretion of glucocorticoids in PTSD, this could only be the case if PTSD somehow increased hippocampal sensitivity to glucocorticoids, for which there is little evidence.

It is clear that psychological trauma can affect brain structure as well as function. Research into the impact of trauma on the brains of infants provides some useful data to consider when considering neurological or biological explanations of changes to the brain structure. Infants who have experienced PTSD have smaller intracranial and cerebral volumes than those who have not (De Bellis et al., 1999). Research with infants has also shown that chronic fear responses can lead to the over activation of the regions associated with fear to the detriment of information processing in other areas of the brain (Perry, 2001). There is also some evidence that suggests the fear response in the hypothalamic-pituitary-adrenal axis can erode the hippocampus region (Perry 2000). Both of these are hypotheses that have been put forward for the mechanisms by which PTSD leads to dementia. However the extent to which evidence from infant studies can be relied up to explain the association between PTSD and dementia in adults is limited.

If the explanation for the association is indeed a biological one we should expect the association between PTSD and dementia to be type specific, since the various dementia subtypes impact brain structures differently. This has already been pointed out by various researchers in the field (Dallam 2011). A differentiation between the dementias is useful as the dementias are generally understood to have different neuropathologic presentations (Pillon et al., 1993). There is some very limited evidence for the thesis that raised cortical levels in PTSD are the cause of a higher risk of dementia, with a suggestion that subcortical dementias are more closely associated with a PTSD diagnosis than other types of dementia (Dallam et al., 2011). Vascular dementia in particular had the strongest relationship with PTSD. This data has to be treated with caution as i) the evidence is limited ii) the extent to which the distinction between subcortical and cortical dementias is valid has been challenged (Hughes et al., 1993; Turner, 2002). Further, the much larger, more robust Yaffe et. al. (2010) study found an ‘across the board’ association, not specific to a dementia subtype, impacting on the extent to which a biological explanation is a cogent one.

Conclusion

There is evidence to suggest the existence of a bi-directional association between dementia and PTSD. There are two caveats to note here (i) There is not yet enough evidence to suggest a causal relationship in either direction (ii) the evidence for an association is not equally established in both directions.

The evidence that PTSD leads to dementia is more convincing. The prevalence and incidence of dementia in individuals with a diagnosis of PTSD is high and there is an elevated risk of dementia for those with a prior diagnosis of PTSD. Two recent methodologically robust studies have found a consistent association between a PTSD diagnosis and an increased risk of dementia. Together, these provide credible evidence for PTSD leading to an outcome of dementia.

The evidence that dementia triggers PTSD is less convincing, partly due to methodological weaknesses of the research undertaken so far. Most of the early research in this field consists of case studies, which is not an uncommon trajectory for neurological studies but is not sound enough to draw conclusions from. Further, there is a lack of clarity in the literature in relation to what the onset of PTSD means. Most of the data refers to the 're-enactment' of PTSD with the onset of dementia, others still make reference to the term 'emergence' or 'delayed onset', so the nature of the association is obscure, impacting significantly on any attempt to identify causality.

The explanations for the association in both directions are quite similarly matched. They are tentative, speculative and for the most unconvincing. It is not yet clear in either case what the underlying mechanisms of the relationship are. The strongest arguments put forward are generally neurological: PTSD triggers a process of neurodegeneration which leads to dementia or the reverse: neurodegeneration caused by dementia disinhibits traumatic memories and leads to PTSD. The neurological similarities between the two conditions make either prospect a plausible but unsubstantiated hypothesis.

Underlying shared risk factors between the conditions

We must be cautious in drawing conclusions regarding causality. Rather than a genuine positive association between the two conditions, it is possible that underlying vulnerability factors may be the cause of both conditions, a fact which has been raised by the researchers themselves in the literature (Yaffe et al., 2010). One of the biological similarities noted between PTSD and dementia is reduced hippocampal volume. However, there is evidence to suggest that people with smaller hippocampal volume have an elevated risk for developing PTSD (Chao et al., 2014; Apfel et al., 2011; Gilbertson et al., 2002). Therefore, instead of being an outcome of PTSD, a smaller hippocampus might predispose to both PTSD and dementia.

While we have seen suggestions that cell loss and atrophy caused by dementia disinhibits emotional memories there is also evidence to suggest that PTSD acts as a disinhibitor. It is believed that in PTSD the amygdala experiences less restraint from the medial prefrontal cortex (the area of the brain responsible for decision making, complex planning and social behaviour moderation), so that otherwise safe or unclear stimuli are more prone to being misread as threatening. If both dementia and PTSD are believed to act as disinhibitors then perhaps it is not one leading to another but an underlying mechanism that causes both to act as disinhibitors. The association between PTSD and dementia might therefore not be etiological but more similar to autoimmune disorders in which individuals with one autoimmune disorder are more likely to develop a second autoimmune disorder due to a combination of genetic and environmental factors.

Future direction of research

A key area for further exploration is for there to be greater distinction drawn between the various dementias in future research. Dementia is a generic term referring to several diseases with differing pathways. In drawing an association between PTSD and dementia, greater attention needs to be given to establishing whether there is a stronger link between one type of dementia and PTSD than another so that we can understand the specific underlying neurochemistry or neuropathology which leads to the association. There is some effort in this regard currently. Hasegawa's early (2007) study linked chronic stress with

Alzheimer's disease. The Dallam (2011) study found a particular association between PTSD and sub-cortical dementias, although this was a small study and the much larger Yaffe study found an association across the subtypes of dementias(2009). Most studies have simply tried to establish whether there is a link between PTSD and any dementia. At the moment, this appears to be primarily just a natural consequence of the stage which the research has reached so far, rather than an oversight by researchers. The research in this field is still in its early stages. This would also explain the preponderance of case studies in the literature, as case studies often form the beginning of research, particularly neurological studies.

Clinical implications

There are clear clinical implications of the potential association between PTSD and dementia, such as screening for PTSD when assessing for dementia. Currently dementia assessments follow a fairly standardised procedure. Persons experiencing memory problems are screened for depression and anxiety to tease out organic from functional causes of cognitive decline. Further, depression and anxiety are also often co-morbid with dementia, and clinicians are usually skilled at teasing out the variant interactions and presentations that can complicate a diagnosis of dementia. However, there is less knowledge about the relationship between PTSD and dementia.

Recommendations

A key recommendation of this research to clinicians is to screen for current and previous PTSD when undertaking memory assessments. Another is for health professionals to be mindful of the association between PTSD and dementia when working with older adults and working with vulnerable groups such as veterans. With knowledge of how PTSD interacts with dementia, clinicians can work towards preventative care in a field which is of huge significance to public health. As pointed out by researchers, if PTSD is a cause of dementia, then it is likely there is a long period of incubation in which treatment for PTSD can reduce the risk of developing dementia. Particular care should be taken with high risk groups such as survivors of sexual abuse, torture survivors and veterans to take into account their elevated risk of developing dementia. Such knowledge can also help clinicians to improve levels and accuracy of diagnoses. For example, it may be the case that a

reoccurrence of PTSD symptoms in older age might act as an early warning signal for neuro-degeneration and an individual should be monitored for cognitive decline and or the onset of dementia. Clinicians should ask about any previous diagnosis of PTSD as well as consider if the individual in question has had any previous traumatic experiences with a view to exploring potential undiagnosed PTSD.

Additionally, in terms of care for people living with dementia, staff involved in managing any behavioural interventions should consider recurrence of PTSD symptoms and incorporate this in to interventions. Night-time support should be provided for people with dementia and PTSD symptoms if it is required. It is important to consider whether restraint or other behaviours of care-givers can trigger PTSD symptoms. Several of the case studies have noted how the environment brought about disturbing memories. There may be several steps care-givers can take to lessen agitation as well as steps they can take to avoid triggering PTSD.

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Appendices for Literature Review

Appendix A: Quality Criteria (Case studies)

Quality criteria				Journal article				
	Duax et al. (2013)	Jacobs & Dinoff (2012)	Maia et al. (2007)	van Achterberg (2001)	Mittal et al. (2001)	Johnston (2000)	Hamilton & Workman (1998)	Mccartney & Severson (1997)
Is the report easy to read?	+/+	+/+	-/-	+/+	+/+	+/+	+/+	+/+
Does it fit together, each sentence contributing to the whole?	+/+	+/	+/-	+/+	+/+	+/+	+/-	+/+
Does this report have a conceptual structure (i.e. themes and issues)?	+/+	+/-	+/+	+/+	+/+	+/+	+/+	+/+
Are its issues developed in a series and scholarly way?	+/+	+/-	+/+	+/+	+/+	+/+	+/+	+/+
Is the case adequately defined?	+/+	+/+	+/+	+/+	+/+	+/+	+/+	+/+
Is there a sense of story to the presentation?	+/+	+/+	+/-	+/+	+/+	+/+	+/+	+/-
Is the reader provided some vicarious experience?	+/+	+/-	+/-	+/-	+/-	+/-	+/-	+/-
Have quotations been used effectively?	+/+	+/+	+/-	+/+	+/+	+/+	+/+	+/+
Are headings, figures, artefacts, appendices, indexes effectively used?	+/+	+/+	+/+	--	--	--	--	--
Was it edited well, then again with a last minute polish?	+/+	+/+	-/-	+/+	+/+	+/+	+/+	+/+
Has the writer made sound assertions, neither over - or - under - interpreting?	+/+	+/-	+/+	+/+	+/+	+/+	+/+	+/+
Has adequate attention been paid to various contexts?	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-
Were sufficient raw data presented?	+/+	+/+	+/+	+/+	+/+	+/+	+/+	+/-
Were data sources well chosen and in sufficient number?	+/+	+/-	+/-	+/+	+/+	+/-	+/+	+/+
Do observations and interpretations appear to have been triangulated?								+/+
Is the role and point of view of the researcher nicely apparent?	+/+	+/+	+/+	+/+	+/+	+/+	+/+	+/+
Is empathy shown for all sides?	+/+	+/+	+/+			+/+		+/+
Are personal interventions examined?	+/+	+/+	+/+	No	No	No	No	Yes
Does it appear individuals were put at risk?	No	No	No	No	No	No	No	No

Appendix B: Quality Criteria (Quantitative Studies)

Quality criteria		Journal article			
	Dallam et al. (2013)	Sperling et al. (2011)	Qurashi et al. (2010)	Yaffe et al. (2010)	Tsolaki et al. (2009)
Rationale clearly described?	+/+	+/+	+/+	+/+	+/+
Research aims stated?	+/+	+/+	+/+	+/+	+/+
Ethical issues addressed?	--	--	+/-	+/-	--
Methodology appropriate to research question?	+/+	+/+	+/+	+/+	+/+
Study design identified and the rationale for choice evident?	+/+	+/+	+/+	+/+	+/+
Experimental hypotheses stated?	--	--	+/+	+/-	--
Key study variables identified?	+/+	+/+	+/+	+/+	+/+
Sample population situated?	+/+	+/+	+/+	+/+	+/+
Selection of participants adequately described?	+/+	+/+	+/+	+/+	+/+
Method of data collection reliable and valid?	+/-	+/-	+/+	+/+	+/+
Method of data analysis reliable and valid?	+/+	+/+	+/+	+/+	+/+
Findings clearly stated?	+/+	+/-	+/+	+/+	+/+
Comprehensive discussion?	+/+	+/+	+/+	+/+	+/+
Strengths and limitations clearly stated?	+/+	--	+/+	+/+	+/+
Justifiable conclusions made?	+/+	+/+	+/+	+/+	+/+

Part II

You are happy and safe: A Discursive Analysis of a Diagnostic Disclosure of Dementia

Abstract

Research indicates that the way in which a clinical diagnosis is delivered impacts on the quality of life post diagnosis. This study explores local and global discursive influences on diagnostic feedback of dementia diagnosis across two NHS memory assessment services. Eight feedback sessions were audio-recorded over a three month period. The recordings were transcribed and analysed using a discourse analytic approach. The transcripts were analysed in terms of their interpersonal and wider discourse features and the ways in which meanings were constructed in the delivery of a dementia diagnosis. The findings suggest that carers, clients and practitioners construct dementia as largely a memory problem, drawing on wider discourses which associates memory with the mind, and that there are interpersonal advantages in downplaying the range of cognitive difficulties that dementia involves. Clinical implications such as post diagnosis procedures and the scope for future research examining the diagnostic delivery methods of different health professionals are presented.

Keywords: Dementia, Diagnosis, Discourse Analysis, Memory,

Introduction

A diagnosis of dementia has not always been given to individuals in the past (Gilliard & Gwilliam, 1996). Patients were often informed instead of a mild cognitive impairment or told that they had 'memory problems' (Bamford et al., 2004; Woods et al., 2003). Some of the reasons cited for this practice are health professional attitudes to disclosure (Carpenter & Dave, 2004) and patients' negative reactions to diagnostic disclosure of dementia (De Lepeire et al., 2007). Over time however, diagnostic disclosure of dementia has become more common and is now recommended as good practice (National Institute for Clinical and Health Excellence (NICE), 2006).

Underpinning the move from non-disclosure of a diagnosis of dementia to the regular diagnostic disclosure of dementia is the ascendancy of philosophical views on person-centred care which seek to centralise the values, experience and individuality of those living with the condition (Kitwood, 1997; Clare, 2003). This approach to dementia care is not without its detractors. From a theoretical and research point of view, there are arguments presented questioning the extent to which the self remains in dementia (Small et al., 1998; Davis, 2004). In response critics have said that the greatest threats to selfhood emanate from the way people with dementia are positioned and treated by professional caregivers (Sabat, 2002).

In giving a diagnostic disclosure of dementia, a key early question for health professionals was to whom a disclosure should be made. Initially it appeared that disclosures were made predominantly to carers and not to patients directly (Bamford et al., 2007). However, it is now recognised that patients with dementia want a diagnosis (Pinner & Bouman 2003; Elson, 2006) and should therefore be included in the diagnostic disclosure of dementia. This has led to a point where the question of how a diagnostic disclosure can best be provided to dementia patients raises itself.

Several studies have explored the difficulties people with dementia often have in recalling their diagnosis (Barrett & Keller, 2006; Robinson et al., 2011). Given the nature of the impairment, it is possible that some people with dementia will perhaps face such difficulties as a consequence of the cognitive impairment inherent in their condition. Alternatively, this poor recall could be related to a tendency amongst health professionals to spend little time on the diagnosis (Karnieli-Miller et al., 2007). Or due to emotional reactions to the news (Aminzadeh, 2007). The general thrust of such research has led to a growing

consensus that diagnostic disclosure of dementia should be viewed as a process rather than as a one-off event (Robinson, 2011). Pre counselling has been shown to have benefits for people due to receive diagnostic disclosure of dementia (Vernooij Dassen et al., 2006). Also, research shows that 12 weeks after the initial disclosure session, clients are more aware about dementia and in a better position to plan for after care (Derksen et al., 2006), although in practice it is not always possible for services to have follow up after sessions.

Most studies that examine the diagnosis procedure (either as a one off session or as an extended process) have tended to explore the accounts of patients and their carers receiving a diagnosis or of the health professionals delivering the diagnosis (Robinson et al., 2011). While a focus on patient and health professional experiences of dementia diagnosis is helpful, there are too few studies in which the unit of analysis is the procedure rather than the patient. Even studies that have set out to identify the disclosure procedure have relied on the subjective recollected experiences of patients and professionals rather than to attempt to record and analyse the disclosure sessions (Robinson et al., 2011). Part of the difficulty in making generalisations about the procedure itself is a lack of standardisation in the way in which dementia diagnosis disclosures are made. The manner in which the diagnosis is disclosed can vary from health professional to health professional and from one session to another. These variations are not only in the content and length of sessions but also in terms of the professional background of the person disclosing the diagnosis to the patient.

By looking at the interactions of health professionals with people with dementia and their carers it is possible to examine the organising principles in clinical encounters. Such interactional processes can be analysed from different methodological perspectives. An audit might be undertaken to examine whether specific topics such as support groups, treatment, and medico- legal issues are adequately and sufficiently addressed by health professionals in diagnosis delivery sessions. One reason this was not chosen as a measure of diagnostic disclosure sessions is that while audits are a good way of seeing whether specific topics are being covered or not, they do not provide a rich picture of all the features of communication that take place within a diagnostic delivery session. Another drawback is that all the emphasis is on what the health practitioner says and does. This approach therefore contains assumptions about the passive role of the client in the diagnostic delivery. Thirdly research in healthcare should provide benefits; it is not clear how generalisable the findings of an audit of one or two trusts would be. And this ties in with another two reasons, one largely practical

that many more interviews would be required, and the other ethical, a lot of data would be collected which wouldn't be analysed for research purposes.

However an emphasis on talk lends itself well to a discursive approach to research which foregrounds language and its uses in analysis.The discursive approach to exploring a diagnostic delivery session looks at the way the meaning of the diagnosis is *constructed* through language rather than viewing the meaning as already set and simply *revealed* through language. The distinction is analogous to the difference between analysing someone giving someone else a cake (was it given at the right moment, did the other person look surprised/ happy to receive it?) or analysing the process of two people making a cake (what is the recipe, who wrote it, how do they take turns with the ingredients, what ingredients do they use to make it; is the work equal; is everyone allowed to use the utensils; what utensils do they have?) From this perspective when practitioners and clients discuss dementia they create its meaning through the course of that discussion.

From its origins in social constructionism, discourse analysis has had two broad trends: (i)Foucauldian discourse analysis which has been influenced by cultural studies and has a greater focus on wider issues of power, society and hegemony and the resources used to construct and maintain dominant discourses and (ii) discursive psychology which is focused more on local everyday situations and the ways in which issues of reality and identity are created in these settings. A useful characterisation between these two trends is capital D discourse for the former trend and lowercase d discourse for the later trend (Gee, 1996; Alvesson and Karreman, 2000). However, there is some overlap with both forms being informed by each other. Further, whether the focus is on macro or micro practices, the unit of analysis is the same: oral or written discourse.

Research aims

This study of diagnostic delivery of dementia focuses on how practitioners, clients and carers obtain a meaning of the diagnosis in their interactions. The focus is on how these meanings are constructed rather than on how they are delivered. Specific research questions to this end are:

- How is dementia described in a diagnostic delivery session?
- How is a diagnosis accepted, resisted or negotiated by clients and carers?

Method

Approach

Discourse analysis was chosen because its social constructionist approach was a suitable method by which to explore the research aims- to understand how the meaning, interpretation provision and acceptance of a dementia diagnosis occurs in practice. Discourse was understood to include both text (including conversations) and broader practices and ideologies which shape the social and physical aspects of reality (Hajer,1995).

Participants

The data used in this study was collected at two National Health Service (NHS) memory assessment services situated in a large urban area of the West Midlands over a period of one year. Participants in the study were staff members, clients and their family members at these services. Client participants were only those who were due to receive a full diagnosis of a dementia. All clients involved in the research were over the age of 60. Six of them were female whereas two were male. In terms of the particular diagnoses being received, five of the clients received a diagnosis of Alzheimer's disease, one received a diagnosis of vascular dementia and two received a diagnosis of mixed dementia.

Process

The research involved contacting clients during the memory assessment process and asking them if they would like to take part in the research . Both memory assessment services follow similar assessment procedures: individuals are referred from General Practitioners (GPs) who provide the service with initial information and relevant medical history. Clients are then allocated to a member of the team to undertake a pre assessment counseling session where the assessment process is explained and information provided to the client. The possible outcomes of the memory assessment are explained and it is checked to see if individuals understand and agree with this process and how much information they would like to receive at the end of the assessment. Options include a full diagnosis, results of the assessments only or to withdraw from the process. Following this, the practitioners collect a relevant history (changes in memory and daily activities). Then clients complete one of two

assessments: Mini Mental State Examination (MMSE) or the Addenbrooke's Cognitive Assessment (ACE-R) and they are then sent for a computerised tomography(CT) scan. The results of the scan, the neuro-psychological assessments and the clinical history are discussed in a multi-disciplinary team meeting, which is attended by a Psychiatrist, Clinical Psychologist, Occupational Therapist and Senior Practitioners (most of whom are Nurses by profession) and. agreement on a diagnosis is reached if possible otherwise further assessment undertaken. The client is invited back in to receive it. A key difference between the services is that there is a continuity of care in one service (A) whereby the same practitioner who undertook the initial consultation and pre assessment counseling meet with the individual to feedback the diagnosis. In the other service (B) the psychiatrist (who has not previously met the client) delivers the diagnosis.

Procedure

Managers at both sites were approached to discuss the possibility of undertaking research at their service. Once they agreed, staff were then contacted in person to see if they would be willing to take part in the research and have a recording made of their dementia diagnosis sessions. They were provided with an information sheet at this stage (see Appendix C). Staff who agreed to participate were asked to sign a consent form. In service A, the practitioner informed clients in the pre-counseling session that research was being undertaken at the service. The clients were given information sheet and invited to take part (see Appendix B). Those who agreed signed a consent form. When a diagnosis was ready, the practitioners checked that a) the client still wanted to receive a diagnosis and b) was still happy for the diagnosis to be recorded

In service B, the client was approached prior to the delivery of a diagnosis and asked by a staff member (me) if they wanted to take part in the research. They were given an information sheet and those that agreed to take part signed a consent form. Before the delivery of the diagnosis the psychiatrist checked that a) the client still wanted to receive a diagnosis and b) was still happy for the diagnosis to be recorded

The diagnostic delivery sessions were recorded on dictaphones by either the practitioner or the psychiatrist. In service A the recording was managed by the Practitioner. In

service B, I set up the recording device and subsequently left the room, returning to collect it at the end of the session.

The diagnoses were delivered by practitioners of different professions. The professionals involved included: an occupational therapist, a psychiatrist, a trainee clinical psychologist and two clinical psychologists. A breakdown of the recordings can be found in Table 1.

Table 1: Recordings and Professions

Profession	Number of recordings	Recordings not used
Occupational Therapist	1	0
Clinical Psychologists and trainee clinical psychologist	3	0
Psychiatrist	6	2

Ethical approval

All participants in the study gave their explicit consent for their data to be used for this research. This research undertaken was proposed to the National Research Ethics Service and granted ethical approval on 8 March 2012 (see Appendix A).

Analysis

10 audio recordings in total were collected. Two audio tapes were excluded because they did not meet the inclusion criteria. One of these was eliminated as it was a diagnosis of Parkinson disease dementia whereas the other diagnosis was not delivered in English. The audio recordings were copied from dictaphones into encrypted and password protected files on computers. Following this, they went sent in encrypted form to transcribers. Personal data was removed from the audio recordings and the transcripts were anoynomised using terms such as family member, client and practitioner in place of names.

The material gathered contained just over 45,000 words of interaction. Discourse analysis was carried out on this material by following several steps (see Table 2). The first of these steps involved looking for patterns and “following hunches” (Wetherell and Potter

1988:177). The transcripts were read for broad themes and initial observation notes were taken at this stage. This involved reading and re-reading the transcripts to obtain a general feel for the data and a sense of familiarity with it Familiarity has been identified as a key factor in being able to locate interpretative repertoires in text (Edley in Wetherell et al., 2001).

Table 2: Analytic Process

Stage		Description
1	Reading of transcripts	Obtain a feel for the data; look for general patterns
2	Reading of focus on Level 1	Highlight constructions of dementia by professional, person with dementia or relative, and persons with dementia
3	Reading of focus on Level 2	Highlight rhetorical & interpersonal goals in the clinical session
4	Reading of levels 3, 4 & 5	Highlight the effects of constructions on interaction e.g availability of subject positions/ identities & on impact of diagnosis on person with dementia e.g post diagnosis legal & social regulation
5	Selection of extracts	Extracts selected in accordance to relevance to the research question, and advice in the discourse research field about distinguishing data from material and pitfalls of overanalysis and underanalysis
6	Re-analysis of extracts	Revisit initial interpretations
7	Re-reading of data situating extracts in original context	Confirm/reject original interpretation

Following this process of obtaining familiarity, the transcripts were read in light of Georgaca & Avdi's (2012) five-point framework (See Table 3). The framework was chosen as a useful tool to organize and to coalesce ideas around. Rather than being discrete, the levels overlap and some features of a particular level are also relevant to another level.

Stage 1-4 of the analytic process involved the analysis of all the data (i.e over 45,000 words of data were reviewed). Stages 5-7 involved the further analysis of selected parts of the data. These selected parts are presented in the findings section of this thesis as extracts. The

extracts were selected from across the transcripts according to how well they related to the research questions and how strongly I believe they illustrate the points and arguments being made in this thesis. In doing so I was guided by the view that 'part of the researcher's task is to establish a connection between the broader topic and argument of the study and what are used as data.' (Taylor in Wetherell et al., 2001 p:28). So from each transcript I selected extracts which were a) relevant to Georgaca & Avdi's (2012) five-point framework and b) relevant to the broader topic and argument of the study.

Table 3: Georgaca & Avdi's five-point framework (2012)

Level	Description	Focus
One	Language as constructive	Discourses, ideological dilemmas , interpretative repertoires
Two	Language as functional	Rhetorical strategies , interpersonal goals, conversational interaction
Three	Language as positioning	Subject positions, identities, voice
Four	Language as power	Dominance , social & institutional practices, genealogies
Five	Effects of Language	Subjectivity, interpellation , location

The hallmarks of good discursive research are internal consistency and rigour (Wetherell et al., 2001) and these were kept in mind throughout the research process including the analytic stage. It was important that the interpretations made in the analysis were grounded in the data. In order to ensure this, transcripts were read and re-read in line with a circular and recursive analysis (Wetherell et al., 2001). Once interpretations of the extracts had been made, the transcripts were returned to and examined in light of these conclusions in order to see if such interpretations were borne out by the context. If the milieu of the text did not support the initial conclusions drawn, then this interpretation was adjusted to something more reflective of the meaning in context. This is in keeping with the principle of circularity and the constant return to the data which is a feature of good discursive research.

When presenting data from across several different speakers across transcripts, quotes derived from various transcripts are a useful way of showing how people largely draw on the

same socially located meanings or discursive resources when they speak. However in doing so there is a danger of falling into what has been termed Under-Analysis through Over-Quotation (Antaki et al., 2003). The danger here stems from the fact that the speech is removed from its original context. One solution to this problem is for the analyst to then return to the original context to show how the claims being made about the utterance fit with its local context. In other words support for the interpretation of the utterance must come from *within* one transcript as well as across them.

Lastly, the data were approached with as little in terms of pre-conceived notions as possible. However it is not possible to eliminate biases and the researcher adopted a reflexive stance whereby her own subject positions were considered. This is discussed in more detail in Appendix F.

Transcription

Following their selection in stage 5, parts of the transcripts that were specifically chosen for further analysis in stages six and seven were then re-transcribed using the Jefferson system (Jefferson, 2004). (A copy of this transcription method is available in Appendix E) The Jefferson system of transcription (Jefferson, 2004) was chosen for this research as the quantity of detail is not overly complicated. It is important to use a simple system so as not to suggest that the data speaks for itself or to minimise the role of interpretation (Wetherell et al., 2001). It has been pointed out that a complicated system of transcription the can give the impression of scientific objectivity and that the findings are free of subjective interpretation.

Findings

In this section the findings are presented. The findings are categorized under each level of Georgaca & Avdi's five-point framework (2012).

Level 1: Language as Constructive

In this section I present one of the recurrent patterns of word use and imagery related to dementia, i.e constructions of dementia found in the interaction. These findings relate to the research question: How is dementia described in a diagnostic delivery session?

Dementia as memory

A key finding was that dementia was often constructed as a memory problem in feedback sessions. The use of memory as a metaphor for dementia occurred often in the dementia disclosure sessions.

Extract 1.1

P5: What you have is a memory problem(.) which is caused by circulation to the brain.

(Transcript 5, lines 112-114)

Extract 1.2

P5: And we use the term dementia (.) but dementia means memory condition (.) that's all it means.

(Transcript 5, line 211)

Extract 1.3

P5: But any dementia(.) any memory condition is progressive

(Transcript 5, line 734)

Extract 1.4

P6: So it's not as good as it should have been for someone of your age (.) so it's not just your age(.) so you have a memory problem, it is a memory condition.

(Transcript 6, lines 78-79)

Extract 1.5

P7: Now what we need to establish(.)= is whether your memory(.) yes is it's a memory condition

(Transcript 7, line 84)

Extract 1.6

P7: There are some changes(.) and then they can explain and from then we can understand why this memory problem is(.) uhh ongoing

(Transcript 7, lines 216-217)

Extract 1.7

P8: Yes(.) so what I'm trying to say is it's not just your age.
C8: No.
P8: You can't say(.) "I'm getting forgetful because of my age," (.)so there is definitely a memory condition.
C8: Hmm mm.

(Transcript 8, lines 128-134)

Extract 1.8

P8: Dementia means a memory condition(.) which = you know↑

(Transcript 8, lines 248-252)

Extract 1.9

P8: Now(.) in vascular conditions there is no tablet we can give
F8: No
P8: To control the memory(.) you know↑

(Transcript 8, lines 348-352)

The extracts above are taken from across various transcripts and provide an insight into how prevalent the construction of dementia as memory is in diagnostic delivery sessions. See Appendix D, Table 1 for a detailed breakdown of the construction of dementia as memory. The fact that such patterns of speech and imagery are so recurrent across the different sessions, points to the conclusion that 'memory' or 'memory problems' are shared social ways of understanding dementia. However, in line with good discursive analysis, it is necessary to return to the original contexts of some of these extracts in order to obtain support for the interpretation of the construction of dementia as memory. Consider the following longer extract:

Extract 1.10

P5: Now (.)the second support which is this leaflet, is a Dementia Adviser↑ (.) that's her name (.) and number.
F5: Yes.
P5: It's worth giving her a call(.) I really I would recommend that. They will come and have a chat with you and link you into all the various supports that are there.
F5: Right. Okay.
P5: And that's really good.
F5: Are those supports that are free or to be paid for↑
P5: Free, free, it's entirely free.
F5: Entirely free support↑
P5: Yeah(.) they have a memory(.) you know(.) they have support workers who can come and you know give you tips on how you manage the memory and =
F5: Yes.
P5: =ideas about, you know they have these clocks which are easy to look at, diaries, calendars and they have groups as well, like coffee mornings and all these activities which are well worth attending, Okay↑

(Transcript 5, lines 440-442)

Here the dementia advisor is referred to as a memory support worker, with dementia and memory being used interchangeably. Memory and dementia were used interchangeably in several of the interactions. Consider the extract below

Extract 1.11

P8: Now(.) there are issues when you're diagnosed with this condition.
F8: In this one? Yeah.
P8: Yes(.) You need to inform DVLA.
F8: Yes. And do we have to have something from you to say↑
P8: No.
F8: That=
P8: If they want to write to me.
F8: =To say that it's mild or anything↑
P8: They will write to me.
C8: Hmm mm.
F8: Yes. And can you say it's mild, can you↑ Would you say that.
P8: Yes. It is mild. It is mild.
C8: It is mild.
P8: I will say it's mild.
F8: Your memory at the moment.
P8: I will say it's mild.

(Transcript 8, lines 670-700)

In some cases the association was so strong that people were unable to distinguish between the two (see Table 4 for an example).

Table 4: Analysis of construction of dementia as memory

Text (Transcript 3)	Analysis
C3: What's the difference between memory loss and Alzheimer's(.) is it always Alzheimer's↑	memory loss is strongly associated with alzheimer's to the point in which it is difficult to distinguish the two.
P3: It's not always Alzheimer's. There are(.) there are different types of dementia	The question is about the difference between memory loss and alzheimer's but it is implicitly understood that memory loss was used by the speaker to refer to dementia, hence the use of the noun referring to the syndrome dementia rather than to the memory loss used in the previous utterance
C3: Yes(.) that was, that was what I was wondering about.	
P3: Yeah.	
P3: But Alzheimer's is the most common type of dementia.	

In returning to the text, it is evident that there is some support for the interpretation of dementia as memory or memory loss etc. from the way the term is used interchangeably with dementia. Further support for extract 1.10 can be found when the impact on the remainder of transcript 5 is considered.

Extract 1.12

F5: We want to make sure that we give her(.) in fact(.) I was only talking to you yesterday wasn't I↑ about having a lady(.) that lady coming more than once. But I'm not sure that that provision is perhaps the right provision for this(.) if you see what I mean(.) because they can't actually help her with her(.) her physical needs.

P5: Personal care you mean↑

F5: Yeah (.) well, not necessarily(.) not so much(.) but I don't know who would be able to help with this problem with the memory↑

P5: That's Social Services(.) not with memory, they will(.) er help with personal care and supervise medication. This is the number, you know?

F5: Yes, right Okay.

P5: And you can arrange (.) I've written here. This is her diagnosis(.) I've written it and this is the support, Okay↑

F5: Okay.

P5: Now we'll go to this first. This is the Social Services (.) that's the number there. They arrange care packages that means carers can go in up to four times a day seven days a week(.) depending on the need. They'll do an assessment first and then(.) and find out you know.

(Transcript 5, lines 383-403)

Because the health practitioner referred to the Dementia Advisor as the Memory Advisor, the carer was confused as to what help, support or advice with regards to memory the worker could provide. The construction of dementia as memory frequently caused confusion. Given that dementia affects other cognitive functions in addition to memory, there is a risk when constructing dementia as memory that the diagnosis will not be fully understood and repair work will have to take place in the conversation. In the following extract, the practitioner has informed client 8 that driving may become difficult. The client doesn't understand why his driving would be affected and then for a few minutes there is work by the client to show that his memory is good in line 740 and 794. There is finally repair work by the practitioner to explain the non-memory implications of a dementia diagnosis.

Extract 1.13

F8: Hmm.
P8: But it's(.) end of the day(.) it's their decision. They have doctors there.
F8: Yes.
P8: And they will make a decision based on.
[00:09:51]
F8: Yes.
P8: You know. All of this.
C8: I've got quite a good memory actually.
F8: Yes.
P8: So, I'm not saying that you should stop driving.
F8: No.
C8: No.
P8: But what I will recommend is short distances.
C8: Hmm mm.
P8: Familiar routes.
F8: Oh it is.
P8: With somebody beside you on a nice day when you feel well.
F8: Hmm. It is yes.
P8: You know (.) in the main time. This is generally (.) we are leaving it's your decision.
C8: But I have no (.) I have no trouble like if we wanted to go to say to Bournemouth and that. I can remember the route.
P8: It's the motorway driving. I wouldn't recommend it.
C8: I don't like motorway driving anyway.
F8: No( ) he doesn't like it, no.
P8: Oh good. Because there are issues as I said(.) you know. It only takes a split second.
C8: Oh yeah.
F8: I drive as well but I don't want to take it off him if he, as long as he can do it.
P8: Yeah. But why don't you drive if you are able to↑
F8: Well I do.
C8: I don't want her to.
F8: But he, he wants to drive and if he can.
P8: Because I tell you the second implications. Because insurance, you have to inform insurance and that=
F8: Yes.
[00:10:45]
P8: =It will just go up the route.
F8: Oh I see. So it might be better to insure me↑
P8: So you have to make a decision, you know↑
F8: Yes. Yes.
P8: You need to tell them if there's a problem(.) an accident. They will not cover if they know you have this diagnosis.
F8: Yes. Yeah(.)no.
C8: Yeah. I mean I haven't it.

F8: So it would be better if I drove then↑
P8: No, I'm not saying that, you go back, think about it, yeah?
F8: Yes.
P8: And see what you want.
F8: Yes. Yes.
C8: You see I don't(.) I don't have any problems remembers routes or going anywhere.
P8: It's not that. It's reaction time =That's where the problem is.
F8: Yes.
C8: Oh(.) my reaction might.

(Transcript, 8 lines702-800)

The above five extracts are presented within their contexts in order to provide support for the reading of the construction of dementia as memory condition, memory loss, memory problem and memory. All five show how memory is used interchangeably with dementia by both clients and practitioners

Memory as a metaphor for the mind

It is arguable that memory is used as a metaphor for the mind because of its strong association with the mind. Mind and memory are strongly associated with each other in a way that non-memory cognitive functions such as language or orientation are not. Practitioners draw upon the metaphor of memory as it is an available basis for a shared understanding in a way that other clinical markers of dementia are not. Metaphors are often used as interpretative repertoires as they provide useful building blocks for representing objects (Wetherall &Potter, 1988). It is suggested that memory in language can often act as a proxy for the concept of mind. We co-locate both with loss in the sense that we say 'losing my memory' and 'losing my mind'. Linguistically it wouldn't be unusual for someone to comment 'I'm losing my mind', when they are unable to recall information or find objects. Further, brain co-locates with working more naturally than memory, so in extracts 1.14 and 1.15 below, I would argue that both extracts are referring to brain or that the phrasing in both are interchangeable with brain.

Extract 1.14

P1: Because I think if your memory is not working well then you don't [cross talk [inaudible segment]

(Transcript 1, line 346)

Extract 1.15

P1: [...]sort of treatment like groups where you can go to to try and make sure your brain is working as well as it can

(Transcript 1, line 774)

In the following extract, it is noted that memory is placed in opposition to the body, as the mind often is in social discourse. This provides support for the analysis of memory as a metaphor for mind.

Extract 1.16

F5: With regards to this type of condition, is it likely it'll affect speech or does it affect vision. Does it really(.) is it it just purely memory or↑

P5: At this stage, you know, it's memory, but if it causes further you know a stroke or some problem like that, yes, it can then affect=

F5: It can then affect other parts of the body.

(Transcript 5, lines 754-760)

Level 2 - Language as functional

In the previous section there was an exploration of the way in which language around dementia was constructive, with these constructions being traced to their social origins. In this section local or interpersonal features of discourse which consist of the action in speech, i.e. the things people *do* with language, such as attribute blame or take responsibility, are considered. The extracts and information presented in this section have been selected from the rich material in the transcript because of their relevance to the research aim concerned with how a diagnosis is accepted, resisted or negotiated by clients and carers.

Extract 2.1

P7: Do you mind if I ask your daughter some questions?

C7: Not at all, not at all

F7: I think it's worth pointing out you probably have in your notes that we did lose my father=

P7: Yes

F7: Coming up to 2 years ago now and(.) ummm and we've also had quite a lot of stress in the family umm that my mother's eldest niece has been diagnosed with anorexia(.) and that has caused a lot of conflict particularly for my mum worrying about my sister, her her daughter you know↑ her other daughter(.) it's put a lot of pressure and stress on on on my sister and and with her work and everything and I think that that has played a big role, hasn't it mum as well you haven't =

C7: It certainly hasn't helped matters

F7: =No, no
C7: It hasn't no
F7: So adjusting to losing her husband after over 50 years and then with this added and trying to be on her own living on her own and then having this on top of everything else
P7: Mmm, do you(.) how do you feel in yourself, do you feel depressed↑
C7: Um no (.) not often. I do occasionally ((phone ringing in background)) sometimes when I wake up in the morning but(.) because she was sleeping(.) we sleep in the same room you see and I find that I(.)I am much better if I am sleeping in the same room as somebody
P7: Why is that↑
C7: I don't know, I've never worked that one out. Because often in the morning when I wake up I find myself a bit down and I have to get up and start doing things.
P7: How are you eating↑ how is your appetite↑
C7: I'm, it's very good except that it's sweet things ((laughter))
P7: How are you sleeping at night↑
C7: I sleep alright oh because where's oh
P7: That's mine
C7: Oh so sorry
F7: You've got a prescription haven't you?
F7: You did ask that we bring any prescriptions in that she's on=
P7: Yes, yes yes
F7: =That she's on
((paper rustling and cross talk))
F7: I think they, did you ask say did you say, are they sleeping tablets↑
C7: Yes, well he told me that's what they were
C7: Yes it helps me sleep
P7: Yes that's what we want
C7: Well he said that the doctor said it wasn't a strong tablet=
P7: No no
C7: =That I would be alright with it
P7: Now(.) what we need to establish is whether your memory(.) yes(.) >it's a memory condition that you're having that we need to discuss further and address< (.)or whether it is all your anxiety and your depression that has been on going that is causing these problems.
C7: Yes.() I understand(.) yes.
P7: What's your own view↑ Do you think it's all the stress and worry and anxiety, or do you think it's not just that – there is a genuine problem with the memory?
C7: I would have said there was a genuine(.) I mean that has not contributed (.) I mean that's contributed towards the fact that it's not very good(.) as you say(.) but I get out and about(.) you know↑(.) so…

(Transcript 7, lines 45-91)

In the above extract the action orientation (i.e the goals of the speakers, which are revealed by the words they use) will be examined. Firstly, this extract can be considered to contain *local* rather than *global* features of talk. In other words, this pattern of speech- inviting the patient's views on whether the memory problems are organic or due to anxiety - this is missing from transcripts of the same practitioner's other dementia disclosure sessions. If it is asked: why this speech now, it would not be reasonable to point to broader influences, as it appears to be a particular feature of just this session. Instead I would argue that this speech is driven by factors that pertain to this specific disclosure session. Examining the text closely, the utterances of the carer relating to pressure and stress demonstrate how the meaning of the diagnosis is negotiated in the feedback session, which has been shown to be a feature of previous studies of clinical encounters (Fischer, 2011) and as well as on patient resistance to diagnosis in terms of the resources people have to resist a diagnosis (Ijäs-Kallio et al., 2010).

The practitioner's questions seeking the carer's views arose out of a need for the professional to assimilate the carer's views regarding the difficulties with the passing away of the client's husband, worrying about her sister and her anorexic niece. The utterance from the practitioner that the diagnosis needs to be established (suggesting that it has not been established up until this point) can be seen as an attempt to convince the carer that these views are being taken on board. The interpersonal work carried out here is to incorporate the views expressed about the stress and worries the client has been facing and to assimilate them into the diagnosis. This has been found in previous research - how practitioners frequently incorporate the client's perspective into the diagnosis, minimising the objectivity of the diagnosis (Gill & Maynard 1995).

However being seen to be incorporating the client's perspective into the diagnosis is merely a rhetorical strategy, i.e. it is used to achieve something in the social interaction taking place. The practitioner has not actually used this information in her decision-making processes (indeed the decision would have been already made at a multi-disciplinary meeting), as the utterance ' it's a memory condition that you're having' is missing a conditional such as the word whether or if. Further support for this interpretation comes from utterances shortly afterwards by the practitioner.

Extract 2.2

P7: So (.)that is what we find in this condition and now I'm going to tell you what it is. It is the early stage of Alzheimer's(.) putting everything together.
C7: Mm…
P7: But because I've given you this diagnosis(.) it doesn't mean you don't have to get(.) you know↑ upset or worried.
C7: No
P7: Because you can still lead your life
C7: Um
P7: Happy, live your life in a happy way
P7: And we have to ensure you're safe, Okay? And you can still have all your activities and live as normal a life as you can, with all the supports that's there.
C7: It's (.)and how (.) when do (.) do I have to go and have another scan↑
P7: No(.) you don't need to have another scan.
C7: Really? You mean that won't alter any more↑
P7: Even if it does we don't need a scan(.) Because we know what the condition is.

(Transcript 7, lines 262-276)

The first 'unestablished' diagnosis is occasioned and can be understood by its proximity to its surrounding context, i.e. the carer's remarks about the client's levels of anxiety. The second established diagnosis is at some distance from the earlier talk and therefore the practitioner is unburdened by the interpersonal work needed at the earlier point in order to show that the carer's views were being taken on board. At this stage in the conversation the diagnosis is given more forthrightly. As a result of this analysis, it is argued that the diagnosis of dementia by practitioners is highly indexical or contextual. How and when the diagnosis is given depends on what the clients and carers say in the session. But for the client's and carer's talk regarding anxiety and stress, the diagnosis would have been 'established' earlier. However due to the utterances of the carer, there had to be rhetorical work undertaken by the practitioner - further questions on "how are you sleeping" and "how are you eating" and inviting views on the memory problem in order to seem to have taken all factors into consideration and therefore increase the likelihood that the diagnosis will be accepted.

Also of note are the linguistic choices here. It is likely that the use of the subject pronoun 'we' refers to the medical community i.e. those who examined the scans, and the practitioner is drawing on a medical discourse and positioning herself as an expert. Alternatively it is possible that the practitioner is referring to the occupants of the room in

which case she is constructing a reality of a shared understanding of the diagnosis between all parties, which, once established, will make it difficult for the person with dementia or the relative to bring forward any information or questions challenging the diagnosis.

Emotions Talk

Accounts of dementia in the session sometimes contained 'emotion categories'. It is suggested that these were constructed to give meaning to events. From their organisation, it is possible to understand these to be constitutive and invoked in order to build a sense of what has occurred (Edwards 1999) rather than representing mental or physiological states behind the words. Consider the following extract:

Extract 2.3

P6: Just having a diagnosis of this condition doesn't mean(.) you know(.) everything inaudible 00:15:10) don't have to feel unhappy.
C6: Well I do feel a bit sad.
P6: Don't. Don't. Yes, you will be sad –
C6: Because when I was (inaudible 00:15:18), heavy breathing, I can't walk fast.
P6: But the condition itself (inaudible 00:15:26)(.) what is important is you can still live a happy life (.) That's what we want, you too↑ You can still be happy and safe. Two things that I'm asking. Are you happy? Yes, you are, clearly. Are you safe? (.) And that's what we want. Yes↑

(Transcript 6, lines 349-360)

In the above scenario, the client characterises the delivery of the diagnosis as a sad experience. This is not acknowledged by the practitioner who in contrast defines the client as 'clearly happy'. It is important to note here that the practitioner has no way of identifying whether the client's mood is sad or happy and indeed the best measure of that might be the client's own account. However the practitioner is not interested in identifying emotion. Rather the practitioner is orientating the client to what is normal and important and to a preferred expressed emotional state as an outcome of the diagnosis delivery session. The yes, at the end of the turn is to invite agreement from the client to the construction that has been made. Edwards (1999) notes that one of the functions of 'emotion talk' is to make sense of prior events and construct the meaning of these events. The emotion words on display here are deployed to make sense of the meaning of the diagnosis delivery session as well as the diagnosis.

Extract 2.4

P7: I mean for me I look at two things(.) I mean are you happy↑ are you safe↑ that's about it
C7: Mm
P7: Both boxes ticked fine
P7: You are happy
C7: Yes
P7: You are safe at present

(Transcript 7, lines 626-631)

There is a switch from the interrogative (are you happy) which the practitioner uses when providing an account of her work. In this sense she is constructing an identity for herself as a conscientious and diligent professional. However she does not actually ask these questions before her boxes are ticked and there is a use of the declarative which narrows the range of emotional description that can be given by the client.

Extract 2.5

P7: So (.)that is what we find in this condition and now I'm going to tell you what it is. It is the early stage of Alzheimer's(.) putting everything together.
C7: Mm…
P7: But because I've given you this diagnosis(.) it doesn't mean you don't have to get(.) you know↑ upset or worried.
C7: No
P7: Because you can still lead your life
C7: Um
P7: Happy, live your life in a happy way

(Transcript 7, lines 262-270)

From an interpersonal perspective, there may also be a desire for the practitioner to avoid personal culpability for the emotion description. We find evidence in the text to support analytical interpretations. Consider the following extracts.

Extract 2.6

F8: She did think it could be vascular.
P8: Yes.
F8: Is that what it is↑
P8: Yes.
F8: Vascular.
P8: Yeah (.)You made it easy now, so I don't have to.

(Transcript 8, lines 201-212)

Extract 2.7

P: Umm(.) which obviously is a.()= a bit of a difficult diagnosis to(.)= To give you
C1: Yes

(Transcript 1, lines 13-16)

We can see that that diagnosis is difficult to give and this it is argued due to the fact that the personal culpability for the diagnosis needs to be avoided.

Extract 2.8

P5: And it's vascular, because of all the changes in the scan and all that=
F5: And the scan is showing that↑
P5: So there is a definite memory condition.
F5: Yes.
P5: And we use the term dementia(.)but dementia means memory condition(.) that's all it means.
F5: Yes.
P5: It's not like Alzheimer's which is the good news.
F5: No(.) yes, yes, yes. Good. Good (.)well that's good isn't it↑
C5: Yes.
F5: I mean we didn't really think it probably would be(.)but you don't know.
P5: Yeah, it's not Alzheimer's but any dementia will change with time.
F5: Right.
P5: In vascular dementia there is no medication that I can give(.)you know(.) to slow the decline down(.)unlike in Alzheimer's where we have.
F5: No(.) yes.

(Transcript 5, lines 203-230)

In the above extract it appears that the practitioner does not feel comfortable delivering bad news, so the news has to be good news. She reframes the delivery of vascular dementia as good news because it is not Alzheimer's disease. She uses emotion talk to avoid the identity of someone delivering bad news and instead position herself as bearer of good news. Another possibility is that the doctor - practitioner does not have the rhetorical authority to interpret feelings in the same way that such authority exists for the interpretation of test results and the re-interpretation of the feelings works to reestablish an expert position.

Level 3: Language as Positioning

In this section the range of subject positions available to the different actors (i.e. the person with dementia, relative and professional) will be explored. The findings presented here relate to the research question: What are the identities used by practitioners, carers and clients in the diagnostic delivery process.

Subject positions are identities that are made possible by ideology (Edley in Wetherell et al., 2001). From a discourse analytic perspective, it is ideology that determines the way people experience themselves in the world. These positions can either be adopted actively by an individual, in which case they are known as reflexive, or the subject (in this case the person with dementia) can be positioned by another individual, with the latter known as interactive (Davies & Harre 1990). (See Table 5.)

In the following extract the carer is rebuked by the practitioner for taking away the client's agency. In response to this, the carer repositions herself from an identity of family to her own self switching to the use of the personal pronoun.

Extract 3.1

F7: Erm, I think we need to know everything, the way that it is so that as a family-
P7: As a family↑
F7: as a family, so that we can make decisions, based on
P7: It's not what you want, it's what mum wants(.) Yeah↑ (Client laughs)= But that's what you would like↑
F7: That's what I want(.)no I don't know what –
C7: Yes(.) I think – I think that's good ((laughs)).
P7: Sure.
F7: You're happy with that are you↑

(Transcript 7, lines 193-200)

Table 5: Subject Positions

Speech	Subject Position	Type
as a family(.) we	relative as family unit	reflexive
as a family(.) we	client as family unit	interactive
It's not what you want(.) it's what mum wants.	professional NHS practitioner	reflexive
That's what I want.	relative as individual unit	reflexive
Yes(.) I think (.) I think that's good	client as individual unit	reflexive

Although ostensibly positing the client as agentic, the practitioner speaks on behalf of the client and addresses the carer. Secondly she refers to the client by her proxy identity in relation to the carer rather than using her name or title. The practitioner presents herself as a guardian of the client's rights and thus avoids for herself an unwanted identity of a poor professional. Such a reading is bolstered by scant evidence from the transcript that the practitioner works to promote any agency or widen the subject positions available to the client. Rather the practitioner herself positions the client as a frail incapacitated person who must be made safe.

Extract 3.2

P7: I mean for me I look at two things(.) I mean are you happy↑ are you safe↑that's about it
C7: Mm
P7: Both boxes ticked fine
P7: You are happy
C7: Yes
P7: You are safe at present
P7: We have to ensure that carries on(.) That's it.

(Transcript 7, lines 626-632)

We are able to link interaction to ideology here by identifying the social origins of such discourse. The media discourse which constructs older adults as frail (Groombridge cited in Murphy, 2004) is being drawn upon here. At times the practitioner invokes a traditional societal discourse which contains assumptions about older people who, as frail passive objects, are unaware of their own interests and require care and protection. At other times the practitioner invokes consumerist discourse with its focus on the principles of the individual at the heart of social transactions. Competing interpretative repertoires from a consumerist discourse and old people as frail discourse are therefore implicated in the availability and uptake of subject positions of people with dementia in the diagnostic disclosure of dementia.

Given the institutional setting for the diagnosis delivery sessions, it's unsurprising that the medical discourse was another powerful discourse drawn upon when taking subject positions and positioning others. The medical discourse has traditionally abstracted diseases from the person and treated them as distinct entities (Mintz 1992). This tension, between a focus on the disease and a focus on the client, was also borne out in the sessions through the

variable constructions of clients as either subject or object depending on the discursive resources being drawn on. The positioning of individuals as either subjects or objects in health institutions to allocate responsibility has been previously explored, e.g how a patient fails chemotherapy, positioning the client in this context as the subject (Mintz, 1992).

Ageing and Dementia

Much research has been carried out on how medical discourse has pathogised the aging process: the developmental stages of early life are associated with growth while those of later life with decay and how ageing has been associated with disease and incapacity (Biggs & Powell, 2001). This discourse was drawn upon heavily in the identities of clients. Consider the following extracts:

Extract 3.3

C3: Especially(.) I know(.) when(.)when you're(.) sort of(.) well(.) I'm(.) I'll be 73 soon. And(.) er(.) that, that is excuse enough for a lot of people.

P3: Yeah.

(Transcript 3, 264-267)

Extract 3.4

C: Not now(.) Because of my age and my breathing(.) I breathing heavy, I thought

(Transcript 6, line 304)

The statement 'because of my age' does not contain much argumentation or explanation. The more powerful or dominant a discourse the less work that has to be done to construct its meaning. It is taken for granted as common knowledge. A powerful traditional medical/biological discourse has strong associations of inherent deficits in the ageing process. Almost 60% of carers for example across Europe viewed dementia as part of the ageing process (Bond et al, 2005). So a statement like 'because of my age' is understood to represent a much wider and rich discourse on the deficits of older age.

However one of the key priorities of medical practice in dementia is to distinguish dementia from the normal aging process. This task is complicated by traditional understandings of old age. Previous research has shown how clients use the identity of age to resist a diagnosis of dementia (Frank et al., 2006). It is further complicated by the act of describing dementia as a memory problem. Constructing dementia as a memory problem (see section 1) means that practitioners must work discursively i.e. use language to achieve a goal,

to stress to clients that the memory problem or condition being diagnosed is *beyond* expectations for their age, which is often posited by clients. The old identity represents a challenge to the diagnostic identity of the dementia patient so there is further work to construct the problem as a 'dementia' memory problem in opposition to an ageing memory problem or in other words to narrow the availability of the subject position as old.

Extract 3.5

P8: Yes(.) So what I'm trying to say is it's not just your age(.)=You can't say, "I'm getting forgetful because of my age," (.)so there is definitely a memory condition.
C8: No= Hmm mm.
P8: And we have to address it (.) and see what we can do about it(.) if there's any, you know↑ Medication or any help↑

(Transcript 8, lines 128-137)

Extract 3.6

P1: probably show that rather than just(.) your brain being older, like, you know, all of us our brain gets sort of older (.)and a bit less efficient(.) that the particular difficulties with memory and with following through on some tasks(.) probably make it more likely that it's (.)Alzheimer's

(Transcript 1, lines 187-189)

Extract 3.7

P7: The score was 80 out of 100
C7: Mmm
P7: Which is not something someone of your age would get(.) you know↑
P7: If someone of your age did that test like that(.) they would have scored much more

(Transcript 7, lines 122-125)

Extract 3.8

P5: But again(.) if someone of your age did the test they will score a bit more(.) so it's not just age.
F5: Oh(.) right.
P5: So you can't just say, Oh this is just because of her age (.) she's doing you know not that well(.)it's not (.) so there is a memory condition -

(Transcript 5, lines194-199)

What is of note here is that the practitioner sometimes adopts the voice of the client and prevents them from adopting this identity for themselves. Such ventriloquism, aside for the questions it raises about agency and the impact it has on subjectivity, is revealing in its work to narrow the range of subject positions available to the client. The practitioner appropriates the voice of the client in order to limit the range of that voice, which the practitioner feels perhaps unable to accomplish through her own voice. This structuring of the

sentence is a grammatical choice. It would be possible to phrase the sentence using her own voice.

In summary, the positioning of clients in the diagnosis sessions was more interactive than reflexive (Davies & Harre, 1990). Clients were often positioned as objects rather than subjects and much talk was directed at carers. Paradoxically, practitioners also often rhetorically positioned the client as independent, capable and able to make informed decisions, perhaps to distance themselves from accusations of not practicing person-centred care and to resist an unwanted identity of poor communicator/professional. The various identities available in the diagnostic delivery session are an outcome of the conflicting nature of social discourse which gives rise to ideological dilemmas or competing ideas, (Edley in Wetherell et al., 2001). These unresolved ideas account for the variations in identities of practitioners carers and persons with dementia. See Tables 2 & 3 in Appendix D for an example of the analysis of subject positions.

Level 4: Language as Power

The process of giving a diagnosis attaches an identity to the client which he or she must recognise and that others must recognise in him or her. The consequences of the bestowal of such an identity are apparent immediately. Consider the following extract:

Extract 4.1

P7: I'm not saying you have to stop driving(.) You can still drive(.) but you have to let DVLA know (.) and they will get all the reports and tests and all that from us(.) And if you still want to carry on(.) it's entirely your choice. Do you still feel that you're able to drive and you want to drive?

(Transcript 7, lines 466-468)

Extract 4.2

P1: you will need to contact the DVLA
C1: Yeah
P1: to let them know you've got a diagnosis. It does(.) they talk about how they then decide if you can continue to drive or not

(Transcript 1, line 492)

Extract 4.3

P2: you don't drive. you have got to use taxis

(Transcript 2, line 259)

Or consider the post diagnosis discussions around future decision-making.

Extract 4.4

P8: Okay(.) Because there's something called Power of Attorney(.) you've heard of that isn't it?
F8: What's that?
P8: Power of Attorney is.=
C8: Hmm.
P8: If.=
C8: To make decisions for me.
P8: You make, you nominate someone=
F8: Yes.
P8: And say that in future if I need someone to handle my finances or make medical decisions.
C8: I'm quite capable actually.

(Transcript 8, lines 943-963)

Such acts are rationalised as being carried out in the best interests of patients. However previous discursive studies have shown that while practices and initiatives within the healthcare system often invoke the benefits to patients as their raison d'etre, they are often absent of the patient voice (NCPOP 2009). Previous research has shown the impact of the reduction of freedoms post diagnosis (Beard & Fox, 2008; Derksen et al., 2006).

In addition to acts which take away freedoms, the diagnosis also opened up the possibility of financial payments such as Attendance Allowance for supervision and support which can be viewed as a disciplining mechanism that serves to regulate the conduct of people with dementia.

Foucault (1974) argued that increased control over individuals in western states is closely associated with the medical discourse. From this critical perspective, public health systems are conceived as constituting pastoral power which, while making claims to save the individual and community, are mechanisms for the surveillance and regulation of the body. This control over the individual is accomplished primarily discursively through the prevalent rationalities of wellbeing and healthy living. Support for such a reading, for example where the practitioners states that the client's safety and happiness are what is sought (Transcript 7, lines 626-631). However, in the increased governmental control and regulation post diagnosis, the experience may be different. Post -diagnosis, people with dementia can have their behaviour problematized and may be labeled as purposeless and aggressive (Mitchell et al 2006; Dupuis 2012). Other research has described the ways in which surveillance technologies are used to control persons with dementia (Kenner, 2008) and has characterised

nursing homes for persons with dementia as a Panopticion - a place where guardians have an all seeing all encompassing view of their charges (Gubrium & Holstein, 1999). While other research has explored the problematising of consensual sexual contact (Ward et al., 2005) among persons with dementia

Level 5: Effects of Language

Foucault (1974) suggests that statements are judged and valued according to their sites, i.e. by who is speaking. One of the effects of the medical discourse on dementia is that clients' statements are devalued. Consider the following extract

Extract 5.1
C8: Mm(.) yes.
F8: Are you fully understanding what's being said here↑
C8: Oh yes(.) darling.

(Transcript 7, lines 352-354)

In the above example the client had previously expressly stated that she did not want medication. The carer then reframes this expression of will as a lack of full understanding. This is an example of how statements from people with dementia can be undermined due to their authors' positioning and the impact it can have on their relationships. The diagnosis can be used as a rhetorical device to question the value and authority of future statements. As the conversation continues there is more evidence of this.

Extract 5.2
P7: Sometimes it's too much information ((laughs)) given all at once,(.) you know (.) ask me any question you need to(.) while I write this out for you…
F7: But the medication will slow(.)or(.) has a chance in a lot of people of slowing down this condition ↑
C7: I understand that.

(Transcript 7, lines 355-358)

The practitioner places the information as being too much, as opposed to the brainpower being too little, which at first blush can be seen to be destigmatising because the locus is on the information rather than the individual but such a construction can also easily be read as an elliptic one: as too much information [for your capacity].

The carer then continues to construct the person with dementia as unthinking.

Extract 5.3

F7: So(.) erm(.) I think that to dismiss medication(.) without even you know↑(.) thinking about it(.) is probably a little bit -

P7: Yeah, what I'm going to suggest here is, let's not push for it today. Because you're not very happy, but I'm not going to discharge you. I'm going to offer you a further appointment =

F7: Okay(.) Okay

P7: =in three or four months. You go back(.) have a chat(.) look up about it(.) if you want to read, I'll give you some you know websites you can read up. Okay↑

C7: Mm.

F8: Yeah(.) Okay.

P8: Come back and see me and if again you say, Doctor, I still don't want it and if you've got all the support that you need, fine, then you can get discharged from the clinic(.) Is that good?

C8: Okay(.) yes.

F8: That's a brilliant compromise, yes.

P8: We'll do that.

F8: Yes, that's brilliant.

P8: Yeah↑ I may get told off for doing that you know(.) because our clinics are so busy(.) but it doesn't matter(.) It's what's best for you.

C8: Mm.

F8: All right↑

C8: I've always felt the same(.) I don't like taking any medicines at all.

(Transcript 7, 363-383)

The carer suggests that the person with dementia has declined the option of medication without thought. The choice of the word dismiss connotes a snap judgement. The phrasing 'without thinking' might be a surface meaning of 'carelessly' or it may allude to a deeper meaning of the unthinking stereotype often negatively associated with dementia or the discourse of the demented other (Sabat et al., 2011) or as an unthinking opinionated mother. Either way the framing of it as thoughtless by the carer is in contrast to client who frames it as something that she has thought over and adopted as a philosophy over a long period of time. Of note here is how the carer constructions shape the talk and work towards the accomplishment of reviving the consumption of medication by framing the rejection of it as rash.

The effects of the medical discourse on dementia and the subjectivity of clients involve a disempowerment of the client. There is also evidence to suggest that the ways in which people with dementia are spoken to and about can affect their recall and their

performance in interviews (Ramanathan -Abbott, 1994). See Table 6 for a summary of how dementia is construction across the 5 levels of ananlysis.

Table 6: Construction of memory across the analytic levels

Level 1	Level 2	Level 3	Level 4	Level 5
Memory as a metaphor for the mind	Memory problems as incorporating the client's perspective	Memory used to position oneself/ be positioned as forgetful	Memory used to undermine the client's statements	Client recall affected by constructions made by others

Discussion and concluding remarks

Discourse analysis of diagnostic dementia sessions suggests that practitioners construct dementia as a 'memory problem' because it provides them with a powerful yet safe way of explaining the process of neurodegeneration. Memory lends itself as a catch all symbol for the mind and also allows professionals to position themselves as helpful, since memory problems are an early clinical feature of many dementias. Conceptually, the use of memory draws on widely available meanings contained in social ideas on old age. Rhetorically, the use of memory as a metaphor allows practitioners to avoid the identity of diagnosing an unwanted condition.

However the construction of dementia as memory leads to an ideological dilemma for practitioners as they are caught between powerful associations of the discourse on aging and a medical discourse that identifies dementia as a process outside of the normal aging process. Practitioners therefore have to work in a complex discursive environment with conflicting local and global influences on their statements. For example practitioners engage in discursive work to construct dementia as a memory problem for local factors (not wanting to be a bearer of bad news) and then work in the opposite direction to construct it as a not normal memory problem for global factors (due to the influence of medical discourse on dementia).

Age is one of the identities drawn on when they resist or negotiate a diagnosis**.** Due to the strength of the discourse on ageing and the memory loss associated with it, clients can position themselves as old rather than having dementia. Clients also negotiate meaning of a

diagnosis by drawing on the results of previous test results or on their current level of abilities in their accounts. Clients are actively involved in the diagnostic delivery session, contributing to the way a diagnosis is given meaning. However many theoretical approaches on how to deliver bad news position clients as passive subjects suggesting practitioners adoption of top-down prescriptive diagnostic terminology and protocol. These approaches overemphasis the extent to which such practices can be standardised, neglecting that the meaning obtained from a diagnostic delivery session is often highly contingent and varied.

Perhaps due to the influence of such paradigms in the diagnostic delivery of dementia, clients have a more limited range of subject positions that are available for them to adopt and are more frequently positioned by others rather than having the freedom to position themselves. The use of a diagnostic label attaches identities to clients which are not always welcome. Clients frequently reject these identities through their utterances and actively adopt alternative identities or subject positions when available. Previous research has noted that positive psychological outcomes are associated with therapists helping to widen the number of available subject positions to clients (Madill & Barkham, 1997; Georgaca, 2001).

In this study I aimed to analyze the ways in which dementia diagnosis sessions are 'talked into being'. It was undertaken in the context of a shifting context of practice from non-disclosure of the diagnosis to clients to a diagnosis being given. In some ways the distinction between previous non-disclosure and current disclosure of a diagnosis is an artificial one as linguistic categories and choices and practices remain similar. The terms memory and memory problems, which were commonly used prior to the provision of a explicit diagnosis, still feature heavily in the dementia disclosure session. Adopting an identity of a deliverer of good news and avoiding an identity of bearer of bad news is still an issue for NHS practitioners.

Clinical implications

It might be useful for individuals with dementia to be told about their diagnosis alone first, with the chance to discuss meaning without being positioned by carers as needing protecting. If there are not two people positioning them, clients may have more space to take up subject positions. Several studies have suggested that the expansion of the range of subject positions available to clients can lead to psychological improvements (Madill & Barkham

1997; Georgaca, 2001). Following this the carer can be invited into the room to discuss matters further.

This study suggests that the process of obtaining meaning of a dementia diagnosis is a constructive one. As positive outcomes are associated with the deconstruction of the diagnostic discourse (Dallos & Hamilton-Brown, 2000) it might be that some clinicians from a non-medical background might allow the individual with dementia the space to construct their own meaning. Either this could be part of the delivery of the diagnosis or as part of a post diagnosis counseling session. It might be useful if therapists can help widen the subject positions available to people with dementia. i.e to help them to understanding their diagnoses in way that leads to positive psychological outcomes.

Training should be provided for all practitioners who deliver a dementia diagnosis in order to help and encourage practitioners to explain the prognosis for dementia in a full frank but sensitive fashion. A focus on current memory problems does not make sufficient progress from non-delivery of a diagnosis to the delivery of one. Features of its progression are often left to the imagination which might be more distressing than a sensitive discussion about what to expect.

Research implications

The current research took place in complicated circumstances in the midst of interaction between three individuals. While this allowed the exploration of interpersonal factors in the construction of a diagnosis, the interpersonal need to reach a consensus within a session made it difficult to explore if and how the various parties construct dementia differently. A research project which allows for this exploration would strength the findings of this research. If it were possible to show that carers clients and practitioners construct dementia in very different ways when interviewed separately, it would provide further support for the notion that the interpersonal need of incorporating the perspective of others affects the way in the diagnosis is constructed. Freed from group dynamics, the impact on the range of identities taken up might be significant. For example, would the person with dementia have more reflexive identities when speaking about dementia without the identities of the expert and the carer present?

This study was undertaken with staff members from a range of professional backgrounds. There was some evidence that the different health care professionals approach the diagnostic disclosure of dementia differently but this requires further research with

greater numbers of staff members and a design that specifically contrasts their approaches. A study design that had greater numbers of these professionals could contrast their diagnostic delivery sessions and look more closely at whether practitioners from different professions approach the diagnosis of dementia in different ways. This can be linked to ideology by considering the different discourses practitioners draw on (e.g a counselling discourse verses a medical discourse when delivering a diagnosis). In a resource stretched NHS environment it is probably worthwhile to know what the impact of different professions are and what types of professionals provide best value for money and best outcomes for clients.

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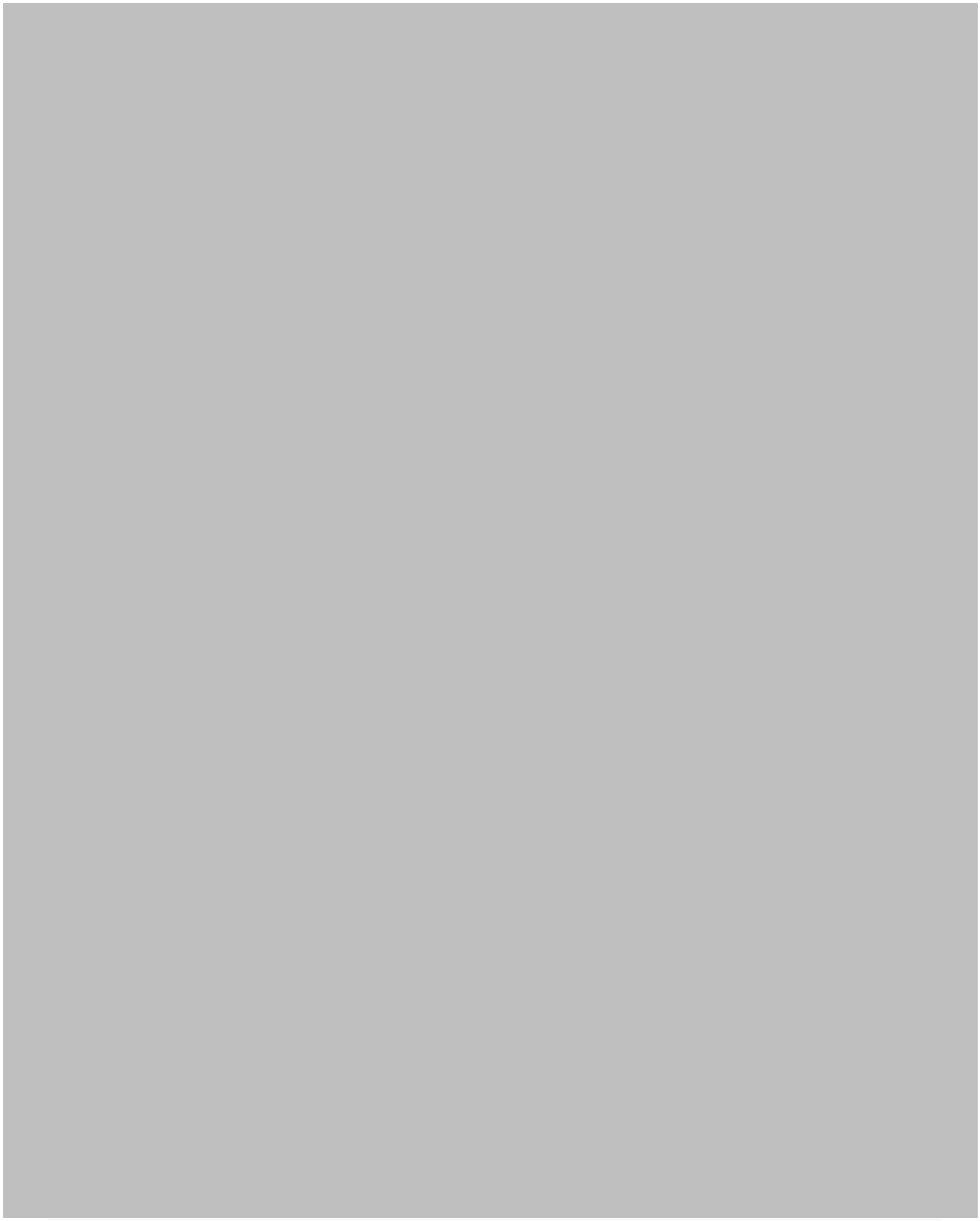
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Appendices for Empirical Paper

Appendix A (Ethical Approval Letter)



Appendix B (Information Sheet for Participants)

Postgraduate Research Study

Disclosing a Diagnosis of Dementia: the effects of listening to a recording of diagnosis

INFORMATION SHEET FOR PARTICIPANTS

You are invited to participate in this research project. Before you decide if you would like to take part, it is important that you understand what your participation will involve and why this research is being carried out. Please read this information sheet carefully and discuss it with your senior mental health practitioner at Birmingham Memory and Assessment Service (BMAAS) if you wish. Please take time when deciding whether or not you would like to take part. Choosing not to participate in this research will not disadvantage you in any way. Please contact me if anything is unclear or if you would like more information.

Why have I been chosen?

You have been invited to take part in this study because you have been referred to Birmingham Memory and Assessment Service (BMAAS) for an assessment of your memory. One of the possible outcomes of such an assessment is a diagnosis of dementia. If this is the case, we would like to record this session to see if those given a recording find it helpful. Research has shown listening to a recorded disclosures of diagnoses of other conditions has been helpful to people.

What is the purpose of this study?

This aim of this study is to find out if listening to a recording of a dementia diagnosis session is helpful to people. We are particularly interested to know if listening to a recording of your consultation helps you better understand the results of your tests, improve you psychological wellbeing and leaves you feeling more satisfied with your consultation

What will your participation involve?

If you choose to take part, and if you are to receive a diagnosis of dementia, permission will be sought from you to record your disclosure session. You will also be asked to complete four short questionnaires after your disclosure sessions. At this point only half of the participants will be sent a recording of these sessions. This half will receive these by post the week following their diagnosis session. The other half will receive their recording at the end of the research process. All participants will be contacted by the principle researcher in order to arrange a convenient time and place to meet to complete the final set of questionnaires 3 weeks after their diagnosis. This meeting will take approximately 30 minutes and it will involve filling in

the same four questionnaires with one additional one for those who were sent their recording to listen to.

If you agree to participate in this study, information from your assessment will be accessed by the researcher for the purpose of this study. However, all information will be anonymised, so that you will not be able to be identified.

Please be aware that:

- You can choose to withdraw from this study up until 6 months after the last meeting without giving any reason.
- You do not have to answer any question that you do not wish to answer.
- Your name and any other identifiable information will be removed from the information that is anonymised so that it is not possible to identify anyone from the reports produced for this study.

When and Where Will the Study Take Place?

Some of the data for this study will be collected from the standard procedures undertaken during any memory assessment. You will be asked to complete an additional 4 questionnaires directly after the diagnosis session. This will be done at the clinic in which your assessment will be carried out. The last set of questionnaires will be completed at a place convenient to you. This can be at your home, or at another suitable venue convenient to you.

How Long Will the Study Last?

A standard memory assessment takes roughly 4 weeks. If you choose to take part in this study, your assessment will not be any longer. However, you will be asked to meet once with a researcher 3 weeks following the end of your assessment to complete the last set of questionnaires. After this one occasion, you will not have to meet anyone again and will have completed your part in the study.

How Will We Maintain Your Privacy and Confidentiality?

Identification numbers will be allocated to all participants to ensure confidentiality of personal data. All data collected during the research process will only be labelled with this number and no other identifying information. Participant identification numbers and contact details will be stored in a password protected participant database, which only the researcher and supervisor will have access to.

All data collected will be confidential and any data that is published will be anonymised. Names or other identifying information will not be included in any reports that are written. Participant details will be destroyed 1 year after completion of the study.

Are There Any Risks Involved in Participating in This Study?

Receiving a diagnosis of dementia can be a difficult time for most people. In addition to this expected level of distress, those who choose to take part in this study may find listening to a recording of their diagnosis session additionally distressing. You might also find filling in some of the questionnaires distressing as they include questions that relate to your new diagnosis.

Are There Any Benefits Involved in Participation?

You might find it useful to listen to the recording of your diagnosis. Research (in other conditions) has found this to be the case for others who have listened to recordings of their diagnosis sessions. You might find that it improves your understanding of dementia and helps to you to remember what was discussed during the session. You might also find it a useful way of sharing your diagnosis with significant people in your life, should you wish to do this.

Who is Organising and Funding This Research?

This research is being carried out as part component of a Doctorate in Clinical Psychology at the University of Birmingham. It has also been ethically approved by the NHS.

What Will Happen with the Results of the Study?

The results of this study will be submitted to the University of Birmingham as part of the academic requirements for the Doctorate in Clinical Psychology. The results may also be published in dementia related journals as well as presented at relevant conferences. A summary of the findings will also be sent out to all participants who wish to have one upon completion of the study.

What will happen to the audio-recordings of my appointments after the study?

As there will be audio-recordings made of the appointments when you receive and discuss your diagnosis, we think it could be useful for a future researcher to look at these. This would enable us to gain a better understanding of how these conversations take place. It might allow us to draw conclusions about how best to talk about diagnosis. We would therefore like to give you an option of agreeing for your audio-recordings to be transcribed and analysed at a later date. The student who undertakes this future research will not know your personal details as s/he would work only from the recordings.

What if I have any Further Concerns?

It is up to you to choose whether to take part in this study or not. If you do choose to take part, you are free to withdraw at any point up until 6 months after the last meeting without giving any reason. If you choose to withdraw from the study, your data will be withdrawn and destroyed.

If you choose to take part in this study, you will be asked to keep this information sheet and to also sign a consent form.

You may contact University of Birmingham on the details below for further advice and information.



Thank you for taking the time to read this.

Appendix C (Information Sheet for Service Provider Participants)

Postgraduate Research Study

Disclosing a Diagnosis of Dementia: the effects of listening to a recording of diagnosis

INFORMATION SHEET FOR SERVICE PROVIDER PARTICIPANTS

You are invited to participate in this research project. Before you decide if you would like to take part, it is important that you understand what this would involve and why this research is being carried out. Please read this information sheet carefully and discuss it with a member of the research team if you wish. Please take time when deciding whether or not you would like to take part. Choosing not to take part will not disadvantage you in any way. Please contact me if anything is unclear or if you would like more information.

What is the purpose of this study?

This aim of this study is to find out if listening to a recording of a dementia diagnosis session is helpful to people with dementia. We are particularly interested to know if listening to a recording helps people to better understand their condition, improves their psychological wellbeing and makes them feel more satisfied with their disclosure session.

Why have I been chosen?

You have been invited to take part because you carry out memory assessments on behalf of Birmingham Memory Assessment and Advisory Service (BMAAS). We would like to record sessions in which you disclose a diagnosis of dementia and provide a copy of the recording to the person with dementia to see if s/he finds it helpful. Research has shown listening to a recorded disclosure of diagnosis of other conditions is helpful to people.

What will your participation involve?

If you choose to take part, you will be asked to record diagnosis sessions for individuals receiving a diagnosis of dementia. This recording will then be sent by post to the individual. There will be no analysis of your recording in this study. This study is simply aimed at understanding if individuals who are given a recording of their diagnosis find it helpful.

If you agree to take part, client information will be accessed by the researcher to ensure the client meets the criteria.

When and Where Will the Study Take Place?

You will be asked to introduce the study to potential participants at the end of the pre-assessment, and asked to record divulgence and support planning. This will be done wherever you hold the appointments.

How Long Will the Study Last?

I aim to start my study later this spring and will finish when I have collected sufficient recordings. I hope this will be by end of September 2012 but if I do not have enough I will need to continue until spring 2013 at the latest.

How Will We Maintain Your Privacy and Confidentiality?

All information will be anonymised, so that you will not be able to be identified in any of the reports produced for this study.

Identification numbers will be allocated to all participants. All data collected will only be labelled with this number and no other identifying information. Participant identification numbers and contact details will be stored in a password protected database, accessible to only the researcher and academic supervisor.

All data collected will be confidential and any data that is published will be anonymised. Participant details will be destroyed 1 year after completion of the study.

Are There Any Risks Involved in Participating in This Study?

Delivering a diagnosis of dementia to an individual is not easy for practitioners and knowing that this sensitive process is being recorded might raise your anxiety levels.

Are There Any Benefits Involved in Participation?

You might find it beneficial to think you are contributing to research that aims to improve services by finding out whether clients and their families find it helpful to have a recording of their diagnosis.

Who is Organising and Funding This Research?

This research is being carried out as part of a Doctorate in Clinical Psychology at the University of Birmingham at the request of the clinical lead in the BMAAS service. It has also been ethically approved by the NHS.

What Will Happen with the Results of the Study?

The results will be submitted to the University of Birmingham as part of the requirements for the Doctorate in Clinical Psychology. The results may also be published in dementia related journals as well as presented at relevant conferences. A summary of the findings will be sent out to all participants who wish to have one.

What will happen to the audio-recordings of my appointments after the study?

The clients will be given a copy of the audio-recording to keep. The research team will also keep an electronic copy of the audio-recording. We think it could be useful for a future researcher to look at these audio-recordings. This would enable us to gain a better understanding of how these conversations take place, as it might allow us to draw conclusions about how best to talk about diagnosis. We would therefore like to give you an option of agreeing for your audio-recordings to be transcribed and analysed at a later date. The student who undertakes this future research will not know your personal details as s/he would work only from the recordings. Recordings will be wiped as soon as this study is complete. If you consent to your recording being transcribed, the transcript will be destroyed after five years.

What if I have any Further Concerns?

It is up to you to choose whether to take part in this study or not. If you do choose to take part, you are free to withdraw without giving any reason, and your data will be withdrawn and destroyed.

If you choose to take part, you will be given this information sheet and will be asked to sign a consent form.

You may contact University of Birmingham on the details below for further advice and information.



Thank you for taking the time to read this.

Appendix D (Example of analytic procedure)

Table 1: Constructions of dementia as memory

Transcript	Notes	Person	Constructions
8	· asks whether explicit diagnosis is wanted but still constructs as a memory problem · dementia defined as memory problem · memory being used interchangeably with dementia · cues on construction picked up by client and carer	p p p p p r c	line 25: You're here to discuss your memory problem. line122: You can't say, "I'm getting forgetful because of my age,": so here is definitely a memory condition. line 238:Dementia means a memory condition. line: 348: there's no tablet that we can give. To control the memory, you know? line: 698-9: Your memory at the moment? (mild) Iine: 92: it's short term, I'm short term memory loss.
5	· carer asks whether it is only memory problems lines as constructions of dementia as memory confuse her. practitioner gives more info but reluctantly · that's all it means- simplification of diagnosis- condensed into memory issue · dementia advisor called memory support worker- keen to avoid term	p p p p p	line 199: So there is a memory condition line 207:So there is a definite memory condition. line 211: And we use the term "dementia", but dementia means line 212: memory condition, that's all it means. Line 457: Yeah, they have a memory – you know, they have support who can come and you know give you tips on how you the memory and... Line 734: But any dementia any memory condition is progressive
7	· memory being used interchangeably with dementia · explicit diagnosis given but still uses term memory condition afterwards · uses current memory problems as a way of talking about the diagnosis- easy to move from current memory problems to diagnosing a memory condition. interpersonal aspects- harder to give explicit diagnosis	p p p p p	Line 84-5: your memory – yes – it's a memory condition that you're having Line 216-7: why this memory problem is on going, Line 217-8: you know, that the memory condition you had is at the early stage. We have three stages Early, you know, like moderate, severe

Table 2: Example of subject positions for transcripts 2, 3, 6 and 7

Transcript	Notes	Person	Subject positions
3	▪ ask questions ▪ reads and interprets information ▪ interprets own symptoms, experiences and capabilities ▪ says there is no family so no need to feel she is guilty. P picks on on this and asks if this is something she has to carry alone. ▪ C worries about leaving the other nuns ▪ self positions more than is positioned (1-12)	p p p p p r c	line 45: noting I can do about it (powerless) line88: I will want to report back to my prevention leader(helpful/ facilitator) line 96: I won't be the first sister (religious, part of a tradition/community) line 145: problems communication and reasoning I don't have much of that (Interpreter/ self aware) line 128: I wouldn't have associated that with memory loss(inquisitive/ amateur scientist) line 242: I do forgot things (forgetful) line 264: I'll be 73 soon and er that's excuse enough... (old) line 308: I still who I am- self accepting line 385: I carry the thing alone line 526: good with words
7	▪ carer speaks often, answers on behalf of client, changes answers of client, leads conversations, interprets ▪ practitioner picks up on client voice not being heard and positions client as independent but also undermines agency of client ▪ carer positions client as being frail and weak minded ▪ client is pressured by carer ▪ practitioner likes identity of helpful/nice	r c p c c r r c p r c c r p	line 20: i live abroad i live in a ski resort (well travelled) line 24:my memory is very very poor (forgetful) line 35: we did some tests on you (client positioned as passive) line 50: adjusting to losing her husband (widow) line 95: I love my own home (independent) line 98: i'm lucky (fortunate) line 104: dad's always done the driving (vulnerable) line 135: mum was finding it traumatic (frail) line 142:I've always been a little anxious(anxious) line 290: I've always been a very very healthy person (healthy) line 295: it's your decision (positions client as agenic) line352: are you fully understanding what is being said here (silly) line 385: I've always believed in the movement of the body (natural) line 428: you go to the theatre and you have friends for lunch (social) line 447: I don't think I'm terribly good with new people (shy) line 470: you're very sensible (sensible) line 482-2: you are computer literate (modern, savvy)

Transcript	Notes	Person	Subject positions
2	· practitioner pushes client to engage with the services on offer, presents it as choice but badgers her · clients age is a particularly strong identity · practitioner mentions it and how consultant thought she was younger · practitioner positions as non-expert sometimes and aligns herself as non-medical staff or approach at other times draws on medical discourse	p p p p p c p c c c r	line 42-3: you were perhaps a bit more forgetful (forgetful) line 75: I was discussing you with our consultant (positioned as passive) line 100: you realised that yourself and you have very good insight (insightful) line115-6 the latest research suggests (expert) line 141-2: you've got a good quality of life (happy) line 144:I think I'm very fortunate (fortunate) line 192: i'll be honest with you (down to earth) line 309: I can't get to these things (isolated) line 345: I don't live extravagantly (frugal) line 361: I don't use public transport, ever since the fall (vulnerable) line 500: as long as I can remember what they tell me (forgetful) line 515: you can give them to me when you come home. I'll sort them out (carer/dependable)
6	· client is meek- asks permission to ask questions · client inclined to take anti-dementia medication at first. strong views of the doctor re side effects make him more hesitant · practitioner cuts off client in speech frequently , ignores his cues and doesn't hear his questions. then asks if he has questions · practitioner asks herself rhetorical questions from the imagined point of view of the client	p r p p c p p r c p c r	line 107 ,176: if you ask me (P adopts clients voice renders him voiceless) line 109: is there anything we can do (helper) line 130: i have to give you the choice (enabler) line 197: it is your view that I want to know (person centred care identity) line 233: you see i don't know (unsure) line 283: you're not very keen at present (positioned by P as anti medication) line 324: And you are therefore coping (coping) line 332: he gets confused now and then (confused) line 352-367: well i do feel sad (sad) are you happy, yes, are you safe yes (happy and safe) line as you can see I'm sentimental (sentimental) he's never had a violent temper or anything like that. he's suddenly stood up and... (positioned as violent, aggressive, unpredictable

Table 3: Subject Positions

Person	Transcript	Number	Type	Main positions
Practitioner	3	2	Reflexive	Expert, non-expert
Client	3	10	reflexive	powerless, helpful religious, old, forgetful, self-accepting, self-aware, clever
Relative	n/a			
Practitioner	7	2	Reflexive	expert, helpful
Client	7	15	7 reflexive, 8 interactive	widow, forgetful, independent, vulnerable, silly, healthy anxious, shy fortunate
Relative	7	2	1 reflexive 1 interactive	modern well-travelled,
Practitioner	2	2	Reflexive	expert, down-to-earth
client	2	9	4 reflexive 5 interactive	old, forgetful, insightful, fortunate, frugal, isolated, vulnerable, happy
relative	2	1	Reflexive	dependable
Practitioner	6	2	Reflexive	enabler
Client	6	10	2 reflexive 8 interactive	sentimental, aggressive, unpredictable , confused, sad, coping
Relative	6	1	Reflexive	helper

Example analysis of transcript 7

F7: I think they, did you ask say did you say are they sleeping tablets?

C7: Yes, well he told me that's what they were. Level 3 – subject position

C7: Yes it helps me sleep

P7: Yes that's what we want

C7: Well he said that the doctor said it wasn't a strong tablet subject position

P7: No no

C7: That I would be all right with it, yes.

P7: Now what we need to establish is whether your memory – yes – it's a memory condition that you're having that we need to discuss further and address, or whether it is all your anxiety and your depression that has been on going that is causing these problems. L1 (construction of dementia as a memory problem)

C7: Yes I understand, yes.

P7: What's your own view? Do you think it's all the stress and worry and anxiety, or do you think it's not just that – there is a genuine problem with the memory? Interpersonal – inviting their views

C7: I would have said there was a genuine – I mean that has not contributed – I mean that's contributed towards the fact that it's not very good, as you say, but I get out and about, you know, so…

P7: Do you drive?

C7: Yes I do. Subject position – independent

P7: And do you go out with friends and socialise and all that?

C7: Yes, yes, oh yes. Not all the time because I love my own home – Subject position independent

P7: Sure.

F7: No but – and you've got a great circle of friends, you've got a lot of family support –

C7: Yes I have, I'm lucky. Level 3 – subject position

F7: - and you do – you are very lucky, you know you do go out and you'll go to the theatre and you'll go to – theatre goer

C7: Yes that's true. I don't drive very far these days, only just the local places that I know very well and if it's going to be far, I shall have to go in somebody else's car and they can do the driving.

F7: Yes, no you don't drive to the South Coast of England or –

C7: No, no I can't go down -

F7: But to be honest with you mum, you would never have done anyway, because dad's always done the driving hasn't he, so –

C7: Yes, he has, that's true. Independent and now vulnerable

P7: And how about your day to day, all the shopping, food, cooking, cleaning all that –

C7: Oh that's no problem. No problem at all, no.

P7: Managing all your bills and finances and - ? You're doing everything?

C7: Oh yes, yes thank you, uh huh.

P7: Now the tests in 2010, you scored 30 out of 30, full score, when the doctor did that test.

C7: Really? I didn't think –

P7: But that's only just a very simple test. They didn't do further, you know, assessments. Test results in prep for bad news

C7: No, no… I do, I remember now, I'd forgotten all about it, yes.

P7: You remember it now? You remember the doctors who - ?

C7: Yes, yes.

P7: Okay now in November, your score went down to 25 out of 30, Okay? It's still Okay, it's not in a terribly low – you can still function well and everything is fine. They did another test with further questions. Do you recall that? This one here where you drew pictures and did all the tests? Yeah? Tests interpreted

C7: Yes (laughs).

P7: You didn't score that well on that.

P7: The score was 80 out of 100.

C7: Mmm…

P7: Which is not something someone of your age would get, you know? If someone of your age did that test like that, they would have scored much more. So we need to establish if when you did the test, you were anxious or – how were you? Were you able to do the test, it was not you who attended? Level less than age! Dementia construction

F7: Unfortunately it was my aunt that was here then and she said she felt mum struggled to do the test. Justifying poor performance

P7: To do the test, mm.

F7: She felt that mum was very anxious and she actually said to me that she felt sorry for her. And she said to you yesterday when we came here, not to worry, you wouldn't have to do it again! Justifying poor performance and resisting diagnosis?

P7: No, no…

C7: (Laughs) She did say that.

F7: So erm obviously I wasn't here to witness it, but that's what my aunt said to me, that it was apparent that mum was finding it quite traumatic. Carer positioning client as frail and traumatised

P7: Mm, now sometimes, you get very anxious about your memory not being good. Level 3 SP

C7: Oh gosh yes. Oh yes.

P7: Is that what's happening with you? Or is it the other way? Is it –

C7: No…

P7: - you get very anxious with every problem you know that's around you and then your memory fails? Or is it – the primary problem is your memory? Level 2 - interpersonal

C7: (Pauses) I can… I have always been a little anxious; it's part of my nature. And certainly things like the little one being anorexic and things – and my daughter, her mother, and that's – and I'm – because my husband was very good to me. That's a mixture, because he would always do everything you see. Anything to do with any papers or anything, he did that and I never – picked up on themes developed by daughter

P7: Had to do it. But you are doing it now aren't you?

C7: Well up to a point I'm doing it, but then I've got a son and three daughters (laughs) and they will help me or do it for me, yes.

Appendix E (Jefferson transcription key)

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TRANSCRIPTION

Jeffersonian Transcription Notation includes the following symbols:

Symbol	Name	Use
[text]	Brackets	Indicates the start and end points of overlapping speech.
=	Equal Sign	Indicates the break and subsequent continuation of a single interrupted utterance.
(# of seconds)	Timed Pause	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	Micropause	A brief pause, usually less than 0.2 seconds.
. or ↓	Period or Down Arrow	Indicates falling pitch.
? or ↑	Question Mark or Up Arrow	Indicates rising pitch.
,	Comma	Indicates a temporary rise or fall in intonation.
-	Hyphen	Indicates an abrupt halt or interruption in utterance.
>text<	Greater than / Less than symbols	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text>	Less than / Greater than symbols	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
°	Degree symbol	Indicates whisper or reduced volume speech.
ALL CAPS	Capitalized text	Indicates shouted or increased volume speech.
underline	Underlined text	Indicates the speaker is emphasizing or stressing the speech.
:::	Colon(s)	Indicates prolongation of an utterance.
(hhh)		Audible exhalation
? or (.hhh)	High Dot	Audible inhalation
(text)	Parentheses	Speech which is unclear or in doubt in the transcript.
((italic text))	Double Parentheses	Annotation of non-verbal activity.

Jeffersonian Transcription Notation is described in G. Jefferson, “Transcription Notation,” in J. Atkinson and J. Heritage (eds), *Structures of Social Interaction*, New York: Cambridge University Press, 1984.

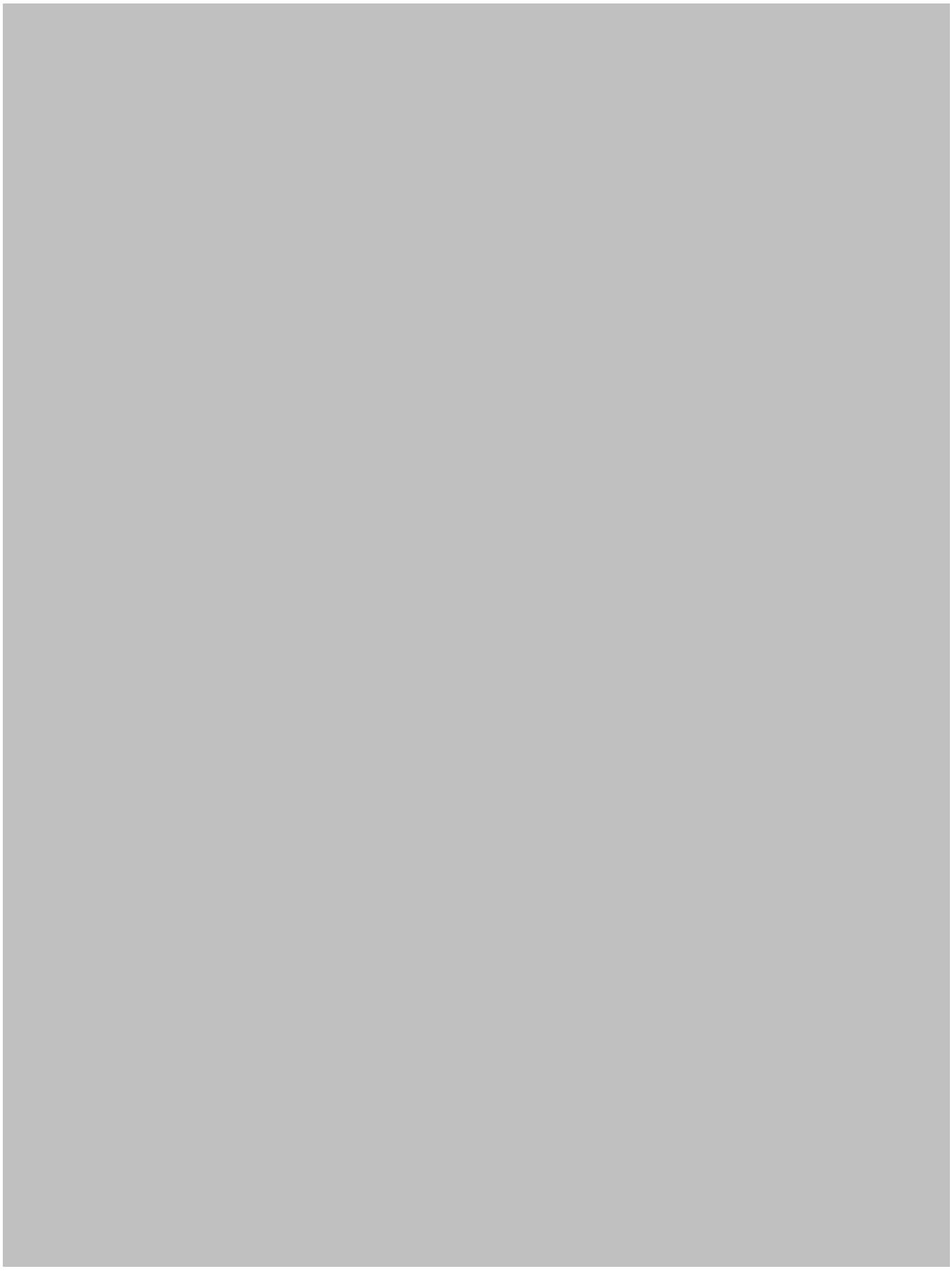
Appendix F (Reflections on my position)

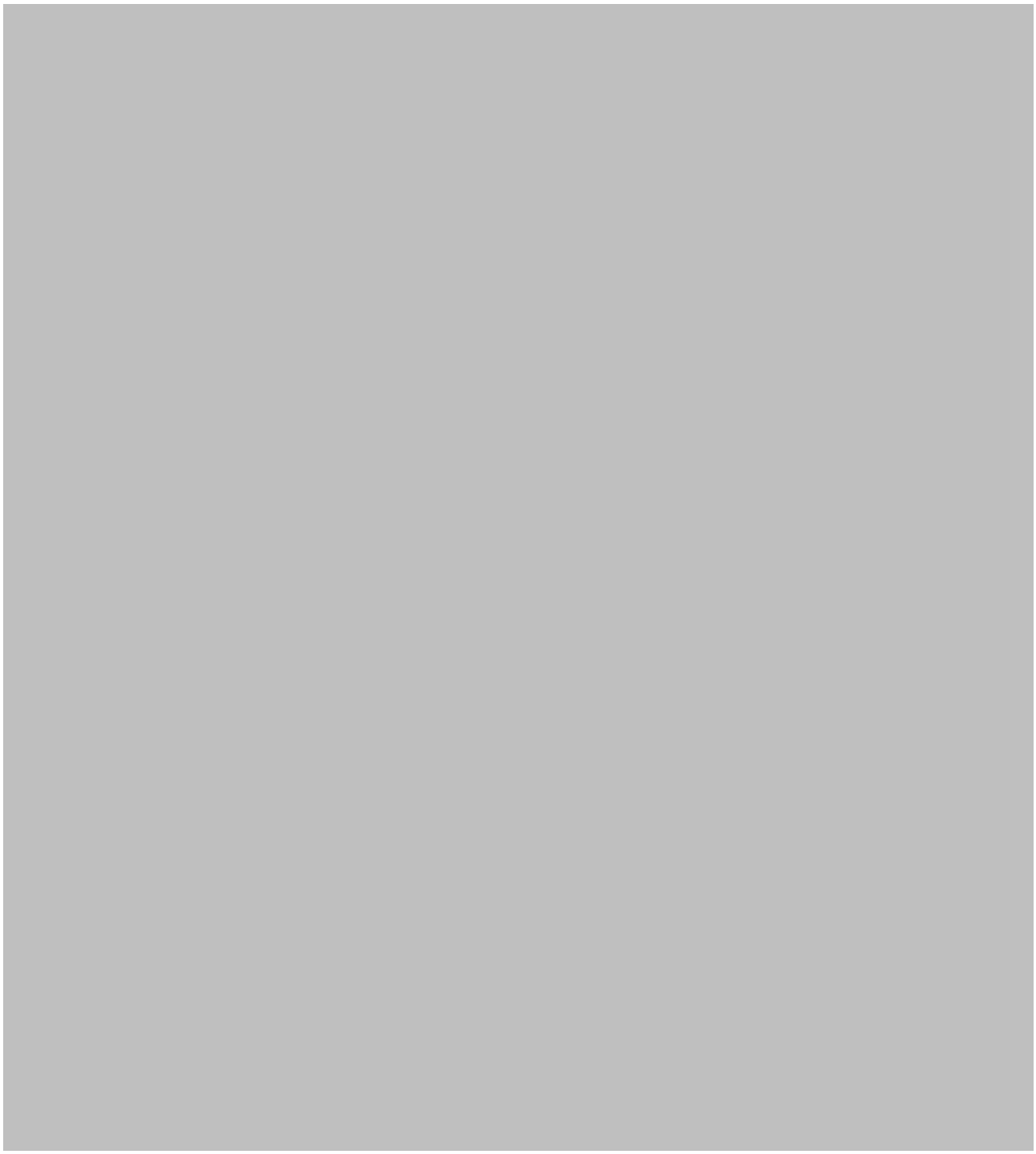
Throughout the research process, and in particular, while analysing the data and writing the research paper, I have found myself reflecting on my own subject positions. The first thing of note is my role as a clinical psychology trainee in service A. As part of my role, I assessed clients and provided diagnoses of dementia. I was also involved in the multi-disciplinary team meetings and knew the other staff who gave diagnoses. I did not have the same familiarity with service B although I did meet with the staff and found that they followed a fairly similar procedure. My having been a team member of one service and not the other may have influenced how critical I was of the transcripts of one service as opposed to the other.

Secondly, coming from a non-medical background may have influenced me to be quite critical of the medical doctor participant in the research and blocked me from making certain observations of the other practitioners. Having regularly delivered diagnoses of dementia, I can certainly empathise with anyone doing so, as I did not find giving such news easy. However as a trainee clinical psychologist I have been taught to communicate a certain way, to have a certain approach to emotions and have strong opinions regarding positioning oneself as the expert in the room vis-à-vis a client. This perhaps does not allow me to be neutral when examining the interactions of a practitioner from a different tradition. I also wonder what I would have found had I analysed a recording of one of my own feedback sessions.

The activity of delivering a diagnosis has traditionally been a medical one and for the diagnostic disclosure of dementia to be carried out by health practitioners from various backgrounds opens up all kinds of possibilities about how to do things differently. Practitioners from different professions are likely to approach the session from different perspectives and with different aims for the sessions. From a psychological perspective, I would privilege the emotional impact of being given such information and provide ample space for the expression of emotion in the room while at the same time trying to give factual information about the diagnosis. My training allows for me to feel comfortable in dealing with emotions but practitioners from other professional backgrounds may not feel as comfortable in this role. When reading the transcripts I may have also been particularly sensitive to the emotions presented or those that are absent from the sessions that were analysed.

Appendix G (Journal formatting requirements)





Part III

Executive Summary

Executive Summary

A literature review of the association between PTSD and Dementia and a research study of a diagnostic disclosure of dementia

Background

Dementia is a growing concern for public health. In the UK, there is a strong governmental emphasis on both prevention and early diagnosis of dementia. Dementia is also a priority globally, with the Word Health Organisation (WHO) declaring it a public health priority and calling dementia 'a significant public health challenge' (WHO & Alzheimer's Disease International, 2012).

On diagnosis, the provision of a diagnosis of dementia is a relatively new phenomenon as due to assumptions about the person with dementia it was not routinely provided to them. One of the key factors in the trend towards diagnostic disclosure of dementia is the rise in popularity in person-centred care and studies in the field of dementia that indicate that people with dementia want a diagnosis (ref). Health professional attitudes to disclosure have also previously been cited as a barrier to disclosure (Carpenter & Dave, 2004). However with the trend now to disclose a diagnosis there is increased emphasis on how to do so. With this move, there is increased emphasis on the talk of practitioners, clients and carer and what is said in such an environment and why. One study revealed that although support for a diagnosis was high- 86% this dropped to 69% when it was an explicit diagnosis of Alzheimer's disease rather than one of memory problems (Elson 2006). Such an environment - where some words seem to be more palatable, more socially acceptable and easier to say than others lends itself well to discursive analysis.

In terms of prevention, one of the risk factors for the development of dementia that has been recently identified is Post Traumatic Stress Disorder (PTSD), which has biological, neurological and demographic similarities to dementia. For many people recovery from PTSD symptoms is within the year, but for some individuals, particularly the sexual abused, war veterans and concentration camp survivors the symptoms can last for many years (Golier et al., 2002). PTSD can have a devastating impact on people's lives, for this reason it is

important to understand if there is a relationship between it and dementia. If a relationship is established, then prevention of dementia can be aided by the proper treatment of PTSD, which will help people doubly: increase the resources and emphasis placed on people with PTSD and help to prevent dementia. Developing an understanding of risk factors for dementia is crucial in the task of establishing protective factors to mitigate a growing problem for western societies.

Systemic Literature Review of the Association between Post Traumatic Stress Disorder and Dementia

As the area is a relatively new topic of research, not much published research was available for review. Thirteen papers were selected for review in order to examine the association between Post Traumatic Stress Disorder (PTSD) and Dementia. A key aim of the review was to consider the strength and direction of any association i.e. the evidence for PTSD leading to dementia and the evidence for the (re)emergence of PTSD following the onset of dementia . The findings from the study suggest that there is more and better evidence that PTSD leads to dementia than the other way around but at this early point in the research it is difficult to draw conclusions.

Empirical Paper: A Discourse Analysis of a Diagnostic Disclosure of Dementia

The study was carried out across two NHS memory assessment sites in an urban part of the West Midlands and looked at the interpersonal and ideological impact on the ways in which a diagnostic disclosure of a dementia was given. Ten diagnostic disclosures of dementia sessions were audio-recorded and 8 were analysed using a discourse analytic approach.

The findings suggest that dementia is talked about as a memory problem and that it is easier to use the term or label of memory problem rather than to refer to the word dementia. The findings suggest that this is the case because it is easier to talk about it in these terms both because clients present with memory problems as one of the early symptoms of dementia as well as because the memory serves as a metaphor for the mind and all its cognitive features more generally. However, using memory interchangeably with dementia can cause confusion for clients and does not help them to fully understand their prognosis.

The results of this study will allow practitioners to reflect on their use of language within the diagnostic disclosure session. While the short-term goals of getting clients to accept a diagnosis may lead them to refer to it as a memory problem, in the long term it is not in clients' interests to understand their diagnoses in terms of memory problems.

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