The Assessment of Pre-morbid Levels of Intellectual Functioning in People with Dementia

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List of Abbreviations

CAMDEX	Cambridge Mental Disorders of the Elderly Examination
CCRT	Cambridge Contextual Reading Test
DRS	Dementia Rating Scale
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders Version Three Revised
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders Version Four
ICD-10	International Classification of Diseases Part 10
IQ	Intelligence Quotidian
GP	General Practitioner
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
NART (-R)	National Adult Reading Test (Revised)
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIGB	National Information Governance Board for Health and Social Care
NINDS/ADRDA	National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association
NoCI	No Cognitive Impairment
PASW	Predictive Analytics SoftWare
PMIF	Pre-Morbid Intellectual Functioning
R & D	Research and Development Office
RBANS	Repeatable Battery for the Assessment of Neuropsychological Status
STW	Spot-the-Word Test
TOPF	Test of Pre-morbid Functioning
WAIS (-R)	Wechsler Adult Intelligence Scale (Revised)
WTAR	Wechsler Test of Adult Reading
UK	United Kingdom

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Declaration

This thesis was carried out under the supervision of Dr Tom Patterson, Mrs Jane Muers and Dr Ian Hume. Authorship of published papers will be shared with the above. The ideas for this research were my own, and developed following discussions with Dr Tom Patterson and Mrs Jane Muers. With the exception of the aforementioned collaborations, the thesis is my own work. This thesis has not been submitted for a degree to any other university.

Ethical approval (Appendices 1-6) was obtained from Coventry University Research Ethics Committee, the Black Country Research Ethics Committee and the NHS Trust's Research and Development Office[1]. Approval was also granted from the National Information Governance Board for support under section 251 of the NHS Act (2006) to process patient information without consent.

It is intended that Chapter 1 will be submitted for publication to the British Journal of Clinical Psychology. Chapter 2 will be submitted for publication to the Journal of Aging and Mental Health (see Appendices 17-18 for instructions to authors).

[1] In compliance with the guidelines stipulated by the NIGB, the locations of the memory clinics have been kept confidential. As such any references to location, including the name of the relevant NHS Research and Development Office, have been removed. This accounts for any blank spaces in the appendices.

Summary

This thesis consists of three papers: a literature review, an empirical paper and a reflective paper. The literature review considers the validity of measures of pre-morbid intellectual functioning with people with varying levels of dementia severity. It aims to be of use to British clinicians by focussing specially on tests that were designed for use with a British English speaking population. No single measure of pre-morbid intellectual functioning is found to be valid for use with people of all levels of dementia severity. The use of multiple measures for estimating pre-morbid intellectual functioning are indicated.

The empirical paper investigates the relationship between a person's pre-morbid level of intellectual functioning and the amount of cognitive decline that they experience prior to gaining a diagnosis of dementia. It uses a retrospective correlational design to analyse data from existing memory clinic files. A significant positive Pearson's correlation coefficient is found between pre-morbid intellectual functioning and amount of cognitive decline at the point of diagnosis, in all three of the diagnostic groups. This suggests that people with high pre-morbid functioning have to undergo greater cognitive decline before they are given a diagnosis of dementia. Changes to current clinical practice are indicated which take account of relative amounts of cognitive decline in the diagnostic process.

Finally, a reflective account is presented which is based on the author's thoughts and experiences of carrying out research in the field of dementia. This focuses on the challenges in accessing retrospective clinical data. Suggestions are made regarding future research and clinical practice.

Chapter 1: Literature Review

The Validity of Pre-Morbid Measures of Cognitive Functioning in People with Varying Levels of Dementia: A Systematic Review of the Literature

KEY WORDS

Dementia; Cognitive Decline; Pre-morbid Intellectual Functioning; Validity.

Word count: 5,287 (excluding abstract, reference list, tables and figures)

ABSTRACT

Purpose

The present paper reviews existing evidence on the validity of pre-morbid measures of functioning with people with dementia. It aims to be of use to British clinicians, by specifically focussing on tests that were designed for use with a British English speaking population.

Methods

A search of databases (including PsycINFO, Web of Science, Cinahl and Medline), citation searches and reference lists was conducted to identify relevant studies. Twelve studies met the inclusion criteria.

Results

Performance on the National Adult Reading Test (NART) and the Wechsler Test of Adult Reading (WTAR) are shown to be affected by dementia, with people making significantly more errors as dementia severity increases. The Cambridge Contextual Reading Test (CCRT) may be a better estimate of pre-morbid functioning, as it produces a higher estimate of reading ability and has a higher correlation with current intellectual ability in the control group. However, performance on the CCRT also reduces with increased dementia severity. An area for further investigation is that of lexical-decision-making tasks such as the Spot-the-word (STW). This has had some promising results and may be valid for use with people with dyslexia. Nonetheless the evidence base for this is small and more research is needed.

Conclusions

The use of objective, pre-morbid measures are vital in diagnosing dementia in order to avoid misdiagnosis. No single measure has been found to be valid for all stages of dementia, and the use of multiple measures may be needed in order to provide an accurate estimate of pre-morbid functioning.

Practitioner Points

Clinical implications

- Performance on both the NART and WTAR is affected by dementia severity.
- Placing NART words into the contextual sentences of the CCRT, produces a better estimate of pre-morbid intellectual functioning. However, CCRT performance is also affected by dementia severity.
- Clinicians should use a number of different pre-morbid measures for more accurate estimates of pre-morbid intellectual functioning.

Limitations

- There is a lack of consistency in the studies reviewed both in the diagnostic criteria utilised and in the labelling of dementia severity.
- Most pre-morbid measures of intellectual functioning have a ceiling effect, above which pre-morbid intellectual ability cannot be estimated.

PURPOSE

Background

Dementia is defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition **(**DSM-IV; American Psychiatric Association, 2000, page 157) as the development of a memory impairment accompanied by one of the following cognitive disturbances: aphasia, apraxia, agnosia and disturbance in executive functioning. The cognitive deficits identified should each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

Presently there is no 'gold standard' for the process of determining levels of pre-morbid intellectual functioning (PMIF). Ideally this would be determined using measures that were taken before any cognitive decline commenced, but in reality it is not possible to predict which individuals will go on to develop dementia, so PMIF is not routinely assessed. Thus pre-morbid levels have to be estimated retrospectively. The difficulty with this is that in order to accurately estimate PMIF, assessment tools need to measure abilities that are not affected by dementia. An overestimate of PMIF could lead to people being wrongly diagnosed with dementia (false positives), while an underestimate could result in people with dementia being missed (false negatives).

Several methods have been proposed to estimate PMIF. These include the use of reading tests with words which do not follow the typical grapheme to phoneme translations, such as the National Adult Reading Test (NART, Nelson & Willison, 1991) and the Wechsler Adult Reading Test (WTAR; Wechsler, 2001); contextual word reading tests such as the Cambridge Contextual Reading Test (CCRT; Beardsall & Huppert, 1994); demographic-based formulae (Wilson et al., 1978;

Barona, Reynolds & Chastain, 1984; Crawford et al., 1989a) and lexical-decision-making tasks such as the Spot-the-Word (STW; Baddeley, Emslie & Nimmo-Smith, 1993).

Validity Criteria

For a measure of PMIF to be valid for use with people with dementia there needs to be evidence that the measure does one or more of the following criteria:

1. It correlates well with IQ scores that were measured prior to the onset of cognitive decline.
2. It produces consistent scores regardless of changes to individuals' dementia severity.
3. It correlates well with measures of current intellectual ability in the control group.
4. It overestimates the current abilities of people with dementia.

Studies which assess the validity of a measure of PMIF for use with people with dementia should address at least one, if not more, of the above criteria. Ideally, for a gold standard level of validity assessment, there should be evidence that the measure addresses all of these criteria. Realistically, however, it is acknowledged that there are limitations to these criteria and that some measures will be unable to produce consistent scores beyond a particular level of dementia severity.

These validity criteria have been developed as a quality framework for the purposes of this literature review, with individual criterion being drawn from the papers reviewed.

Figure 1: Validity Criteria

Rationale

There has been considerable debate as to how valid pre-morbid measures are. Some studies state that performance on measures derived from current abilities, such as the NART, are not affected by dementia (Nelson & McKenna, 1975; Nelson & O'Connell, 1978; Sharpe & O'Carroll, 1991), whilst others disagree (O'Carroll et al., 1995; Stebbins, Wilson, Gilley, Bernard & Fox, 1990; Fromm, Holland, Nebes & Oakley 1991). Conversely demographic variables, which are not derived from current ability, are not affected by dementia. However, Crawford et al., (1989b) found that demographic variables can only account for 50% of variance in WAIS Full-Scale IQ (Wechsler, 1981), whereas the NART was able to account for 66% of variance. It is therefore unclear which method is the most valid.

O'Carroll (1995) critically reviewed studies which used demographic variables, reading ability or lexical-decision-making tasks to evaluate pre-morbid abilities. This included people with: Alzheimer's disease, Huntington's disease, Schizophrenia, Korsakoff's Syndrome, Depression and Glioma. O'Carroll (1995) suggested that there was too much error in the predictive scores of demographic variables, which could result in an underestimation of individuals' abilities. He concluded that whilst the NART was popular, performance on the test may be compromised in Alzheimer's disease. It was suggested that the NART words either needed to be placed into context to improve their validity, or else combined with demographic variables. Additionally lexical-decision-making tasks were suggested as a measure of pre-morbid ability in some individuals with dysphasic, dyslexic or articulatory problems, as people can point to the correct answer. However, the validity of these measures needs to be examined further in people with dementia.

Similarly Franzen, Burgess & Smith-Seemiller (1997) explored some available methods of estimating PMIF. They noted a need to examine different disorders separately, as currently many studies group people in terms of brain-injury versus no brain-injury. They suggested pre-morbid measures can often be influenced by demographic factors such as age and ethnicity, which need to be controlled for. They also highlighted the need to focus on cognitive decline in areas other than IQ, such as memory and executive function. They found that none of the existing measures were optimal for use and that improvements were needed. However, they concluded that current objective measures were still considerably better than relying on subjective clinical judgement alone.

Whilst both aforementioned reviews explored the use of pre-morbid measures with people with dementia, dementia was not the main focus and was often examined as part of a larger 'brain-injury' group. Given that dementia affects cognitive functioning very differently from schizophrenia for example, there is a need to research the validity of measures of PMIF in the assessment of dementia separately. Furthermore, an updated critical review of the research in this area is needed, given that previous reviews only considered literature published prior to 1997.

Not all pre-morbid tests are valid for use with people in Britain. The NART was originally developed using frequently used British words. However, doubts were raised about the transferability of the NART to American populations and American versions were developed, such as The American National Adult Reading Test (Schwartz & Saffran, 1987) and the North American Adult Reading Test (Blair & Spreen, 1989). Tests such as these should be excluded when considering a British population.

Aims

The present literature review aims to critically appraise the validity of measures used to assess PMIF in people with dementia, mindful of the criteria presented in Figure 1. It aims to be of use to clinicians who work in dementia services in Britain; therefore it aims to evaluate only those measures which have been designed for use with a British-English speaking population.

In order to provide continuity with the existing reviews this paper will explore the literature from 1996 onwards.

METHODS

Literature searches were carried out between October 2011 and January 2012, using the databases PsycINFO, Cinahl, Medline and Web of Science. Search terms included 'Premorbid OR Pre-morbid' AND (IQ OR intell*[2] OR funct*) AND Dementia NOT (Schizophrenia OR psychosis). Reference lists of included papers were searched and cited reference searches were made using the Web of Science. The British Journal of Clinical Psychology was also searched using the above criteria, but no additional papers were found.

The search strategy (Appendix 7) yielded 544 papers overall. Abstracts of articles were read to check their suitability for inclusion. Articles were only included if they met the inclusion criteria in Figure 2. Twelve papers met these criteria. The main aspects of these papers are summarised in Table 1.

Papers were included if:

- they were published in peer-reviewed journals
- they were in the English language
- they contained a distinct dementia population
- the measures had been designed for use with a British-English speaking population
- the research evaluated the use of a pre-morbid measure
- the study was published from 1996 onwards

Figure 2: Inclusion Criteria

[2] The * symbol is used to denote a truncation in order to search for any words beginning with those letters

Study	Participants	Mean age in years (range)	Dementia severity	Pre-morbid Measures*	Main findings
Bucks, Scott, Pearsall & Ashworth (1996)	202 subjects: 119 dementia (not specified) 83 controls	Overall mean: 70.1 (44-88)	Not included	Short NART NART	The short NART could not accurately predict scores for the full version of the NART, as it underestimated scores by up to one standard deviation. It was deemed to be unacceptable as a clinical measure in its current format.
Beardsall & Huppert (1997)	20 dementia 61 normal	Dementia Minimal mean: 83.6 (78-95) Mild/moderate mean: 86.6 (79-95) Controls mean: 83.0 (77-94)	13 Minimal 7 mild/ moderate as defined by CAMDEX	NART Short NART CCRT Short CCRT Short Spot-the-Word (STW)	The short CCRT produced a higher estimate of pre-morbid ability in both people with dementia and controls, than the short NART. Short STW performance was good for people with minimal dementia but grossly impaired in people with mild/moderate dementia. It was therefore suggested that each test is only appropriate for specific groups of people.
Paolo, Tröster, Ryan & Koller (1997)	44 Alzheimer's 44 Controls	Alzheimer's Mild mean: 74.04 Alzheimer's Moderate mean:74.20 Controls mean: 73.20	24 mild mean Dementia Rating Scale (DRS) score: 115.38 20 moderate mean DRS score: 99.15	NART Barona demographics (WAIS-R)	NART and Barona demographics both overestimated the IQs of people with Alzheimer's, when compared to WAIS-R IQ. People with moderate dementia scored lower than those with mild dementia on the NART, suggesting that the NART is sensitive to dementia severity. However, given that the scores were still higher than the WAIS-R, the NART may still provide relevant clinical information.

Study	Participants	Mean age in years (range)	Dementia severity	Pre-morbid Measures*	Main findings
Conway & O'Carroll (1997)	30 Alzheimer's	Group mean 72.7	Two groups MMSE < 17 and MMSE ≥ 17 Overall mean MMSE:16.4 (5-26)	NART CCRT	Placing NART words in the context of sentences (CCRT) reduced the number of pronunciation errors made. This effect was largest for the more severe dementia group. Moreover, the CCRT was not correlated to the MMSE whereas the NART was. This suggests that the CCRT is a better estimate of pre-morbid ability than the NART.
Law & O'Carroll (1998)	21 Alzheimer's 114 controls (but reduced to 50 controls when matched to Alzheimer's subjects)	Alzheimer's mean: 77.4 Controls mean: 67.5	Alzheimer's MMSE mean: 17.0 (10-21) Controls MMSE: no mean given (25-30)	NART STW CCRT	All three measures were relatively unaffected by Alzheimer's. Both the NART and the CCRT correlated well with current measures of verbal intelligence in the control group, but the STW had a low correlation. Placing the words in context resulted in 4.4 fewer errors for the Alzheimer's group and 0.8 fewer errors for controls. Overall, CCRT is recommended as the fairest estimate of pre-morbid ability.
Taylor (1999)	43 Alzheimer's 41 Multi-infarct dementia	Alzheimer's mean 75.3 (53-91) Multi-infarct dementia mean 69.5 (37-92)	Average duration of dementia was 3 years	NART Demographic variables (Crawford et al. 1990)	The NART correlated strongly with measures of current functioning, this suggests that it is influenced by dementia severity. To avoid an underestimation of ability, demographic variables should be used either as a substitute for, or in addition to, the NART.

Study	Participants	Mean age in years (range)	Dementia severity	Pre-morbid Measures*	Main findings
Cockburn, Keene, Hope & Smith (2000)	78 Alzheimer's or mixed dementia	Overall mean (at time of entry to the study): 78.63 (60-95)	MMSE scores mean: 14.32 range: 0-26	NART (MMSE)	Four annual assessments were carried out with people with dementia. NART score was found to decline over time. The amount of decline in the NART scores was a function of previous MMSE scores, with greater decline being shown as MMSE scores decreased. This suggests that the NART is associated with current cognitive ability and its validity is compromised as severity increases.
Bright, Jaldow & Kopelman (2002)	32 Alzheimer's 51 controls 64 other conditions (e.g. Frontal lesions, Korsakoff's Syndrome and temporal lobe)	Alzheimer's mean 67.16 Controls mean: 55.39	Mean duration of symptoms: 2.9 years (6 months- 6 years).	NART NART-R Demographic variables (Crawford et al., 1989a; Crawford & Allen, 1997) (WAIS) (WAIS-R)	NART/NART-R had higher correlations with current WAIS IQ in controls than demographics variables. An equation combining NART and demographics did not increase the amount of variance that could be explained. This suggests that the NART is a valid predictor of pre-morbid ability in early Alzheimer's.
McGurn et al. (2004)	45 Dementia (Alzheimer's, vascular and unspecified dementia) 464 Controls	Dementia mean: 79.0 Controls mean: 79.1	Dementia MMSE mean: 22.3. (Mild-moderate). Controls MMSE mean: 28.4	NART	NART scores in both dementia and control groups were compared to an IQ test that was taken at age 11. After controlling for childhood ability, there were no differences between the groups on the NART. The NART is valid as an estimator of ability in mild to moderate dementia.

Study	Participants	Mean age in years (range)	Dementia severity	Pre-morbid Measures*	Main findings
McFarlane, Welch & Rodgers (2006)	66 Alzheimer's: (30 minimal 36 mild) 32 controls	Minimal mean: 73.6 (47-91) Mild mean: 75.6 (47-91) Controls mean: 70.0 (48-84)	Minimal: MMSE 24.6 (24-28) Mild: MMSE 18.6 (14-23) Controls: MMSE 29.5	NART WTAR CCRT STW Demographics regression equation (Crawford & Allen, 1997)	Irregular word reading is compromised in mild dementia. This group performed better on the CCRT than the NART, but still made significantly more errors than the minimum or control group. Demographic variables produced a significantly higher estimate of pre-morbid IQ than the NART in the mild group. There were no significant differences for the minimal or control groups, or when compared to the CCRT. No significant group differences were found on the STW test. This suggests that lexical decision tasks may provide a more accurate pre-morbid measure for people with mild dementia.
Hilsabeck & Sutker (2009) *Demographics from Study 2*	31 dementia: (18 Alzheimer's 10 MCI 1 Vascular, 1 Lewy bodies, and 1 unspecified) 100 controls	Dementia mean: 74.94 Controls mean: 24.68	Dementia MMSE mean: 25.7 (19-30)	Anagrams Solutions WTAR (RBANS) (WAIS-III)	The anagrams solution, is not effective at predicting pre-morbid memory functioning. Whilst there were no significant differences between the groups on the anagrams solutions task, there was a low correlation between this task and other memory tests. Demographic variables and IQ combined, only accounted for between 24% and 31% of variance.

Study	Participants	Mean age in years (range)	Dementia severity	Pre-morbid Measures*	Main findings
Duff, Chelune & Dennett (2011)	1,059 referrals to dementia clinic	Group mean: 71.8	MMSE mean: 24.5 MMSE scores: 18% < 21 23% 21-24 29% 25-27 30% 28-30	WTAR Test of Pre-morbid Functioning Pre-morbid memory equations (Duff, 2010)	Explored the validity of formulae (based on demographic variables and an estimate of pre-morbid intellect) to estimate pre-morbid memory functioning. Large and statistically significant differences were observed between pre-morbid and current memory function. The use of these formulae in future clinical work is supported but some cautions are noted.

*Short National Adult Reading Test (Short NART; Beardsall & Brayne, 1990); National Adult Reading Test (NART; Nelson, 1982); National Adult Reading Test Revised (NART-R; Nelson & Willison, 1991); Barona Demographics Index (Barona et al., 1984); Cambridge Contextual Reading Test (CCRT; Beardsall & Huppert, 1994); Spot-the-Word (STW; Baddeley, Emslie & Nimmo-Smith, 1993); Demographic variables (Crawford & Allen, 1997; Crawford et al. 1989a; Crawford et al., 1990); Anagrams Solutions (Hilsabeck & Sutker, 2009); Wechsler Test of Adult Reading (WTAR; Wechsler, 2001); Test of Pre-morbid Functioning (TOPF; Wechsler, 2011); Pre-morbid memory equations (Duff, 2010).

Table 1: Summary of Included Papers

RESULTS

Assessment of Validity Criteria

Study	Criteria that the study assessed:			
	Correlation with scores produced prior to dementia onset	Use of different levels of dementia severity	Correlation with current abilities in control group	Correlation with current abilities in dementia group
Paolo, Tröster, Ryan & Koller (1997)	✗	✓	✓	✓
Bright, Jaldow & Kopelman (2002)	✗	✗	✓	✓
Hilsabeck & Sutker (2009)	✗	✗	✓	✓
McGurn et al. (2004)	✓	✗	✗	✗
Cockburn, Keene, Hope & Smith (2000)	✗	✓	✗	✗
Beardsall & Huppert (1997)	✗	✓	✗	✗
Conway & O'Carroll (1997)	✗	✓	✗	✗
McFarlane, Welch & Rodgers (2006)	✗	✓	✗	✗
Law & O'Carroll (1998)	✗	✗	✓	✗
Taylor (1999)	✗	✗	✗	✓
Duff, Chelune & Dennett (2011)	✗	✗	✗	✓
Bucks, Scott, Pearsall & Ashworth (1996)	✗	✗	✗	✗

Table 2: Validity Criteria Assessed by each Study

Each of the included papers was cross-checked against the validity criteria set out in Figure 1. The studies have been ordered on the basis of the number of criteria that they assessed for (Table Two). Studies which assessed a greater number of the criteria were deemed to be of a higher quality than those studies which assessed fewer aspects.

The National Adult Reading Test (NART)

Validity with dementia.

Ten of the papers reviewed explored the validity of the NART. Five papers suggested that performance on the NART is affected by dementia and five concluded that it is not. These papers are critically appraised below.

Bright, Jaldow and Kopelman (2002), who assessed two of the validity criteria, found the NART to be a valid estimate of pre-morbid intelligence. They studied groups of people with various conditions including Alzheimer's disease, Korsakoff's Syndrome, frontal or temporal lobe lesions and healthy controls. They examined participants' scores on: the NART (both original and revised versions; NART-R), demographic variables and a combination of both. They compared these scores to participants' current WAIS/WAIS-R scores and to the control group. In the control group both the NART and NART-R had higher correlations with current functioning (r=0.75 and r=0.73 respectively), than either of the demographic variables (r=0.50 and r=0.46). In the Alzheimer's group the NART significantly overestimated people's WAIS/WAIS-R scores. They concluded that the NART is valid as an estimate of pre-morbid intellectual functioning.

Bright et al., (2002) used a relatively small Alzheimer's population (n=32) who were in the early stages of dementia (average symptom duration of 2.9 years). The

authors themselves note that it would be interesting to explore whether or not reading ability deteriorates with increased dementia severity, as they suspected it might. If ability does deteriorate then the NART, which has to be read, would not be valid with people with severe dementia.

Further support for the NART is provided by Law and O'Carroll (1998). They compared the performance of 21 people with dementia and 114 controls, on the NART, the CCRT and the STW. They found that performance on all three measures was relatively unaffected by Alzheimer's disease, as there were no significant differences between the Alzheimer's and control group. Moreover, they showed that scores on the NART correlated well with current verbal intelligence in the control group (r=0.72). As such they concluded that the NART is valid as a measure of pre-morbid functioning.

However, whilst the control group's correlation between NART and verbal intelligence was good, the correlation with WAIS full-scale IQ was low (r=0.55), leaving a lot of variance left unexplained. Given that the NART is used as a predictor of pre-morbid IQ and not just verbal intelligence, it would be expected that this correlation would be higher, raising questions about the validity of the NART.

Furthermore, Law and O'Carroll's control group had a Mini-Mental State Examination score (MMSE; Folstein et al., 1975) of over 24. The authors acknowledge that it is still possible to have significant cognitive impairment with an MMSE score of 25 or above. This potential confound may have contributed to a lack of difference between the dementia and control groups.

McFarlane, Welch and Rodgers, (2006) used a cross-sectional design to study the effects of dementia severity on performance on a range of pre-morbid measures including: the NART, CCRT, WTAR, STW and demographic regression equations. They studied 66 people with Alzheimer's and 32 controls, and separated the dementia group into two stages of dementia severity (minimal: MMSE 24-28 and mild: MMSE 14-23). Overall, they found that the mild dementia group made significantly more errors on the reading tests than either the controls or minimal group. These errors were reduced when the words were put into context, using the CCRT, but the mild group still made significantly more errors. They concluded that NART performance is affected by mild dementia and may not be valid for people with an MMSE score of between 14 and 23.

A criticism of this study is the disparity in the MMSE range of the two dementia groups. The minimal group had a range of 5 MMSE values (24-28), whereas the mild group covered 10 MMSE values (14-23). It is possible that group differences emerged due to the values at the lower end of the range, and that these may not have been present if an MMSE range of 19-23 had been used. Further research is needed to clarify this. Secondly, it would be naive to assume that the NART is valid above a certain MMSE score, but invalid below this. Instead, it is likely that the NART's validity reduces gradually as dementia severity increases, and clinicians should be aware of this.

Paolo, Tröster, Ryan and Koller (1997) explored the validity of the NART, in a sample of 44 people with Alzheimer's disease and 44 controls. They found that NART performance was affected by dementia severity, with participants with more severe dementia (Dementia Rating Scale (DRS) < 110; Mattis, 1988) gaining lower scores. However, given that NART estimated pre-morbid IQ's were higher than

scores of current ability, they concluded that the NART may still be able to provide some relevant clinical information. Of all the included studies, Paolo et al. (1997) assessed the highest number of validity criteria (Table 2), consequently greater reliance should be placed on the findings of this study.

Longitudinal NART Studies.

Two studies employed a longitudinal approach to assessing the validity of the NART. A longitudinal approach provides an insight into how an individual's score changes over time, and removes any between-subject differences.

McGurn et al., (2004) compared NART predicted pre-morbid IQ scores with actual pre-morbid IQ scores (taken from age 11 school tests), in both a dementia and control group. This was the only included study which assessed this validity criterion and as such provides a rare assessment of the NART's validity. The dementia group was classed as having mild to moderate dementia with a mean MMSE score of 22.3. McGurn et al., found that the correlations between NART and age 11 IQ were similar for both the dementia (r=0.63) and control groups (r=0.60). These authors concluded that the NART is a valid measure in people with mild to moderate dementia. However, they did not explore the scores of people with more severe dementia.

Cockburn, Keene, Hope and Smith (2000) explored whether NART scores change with dementia progression. Unlike other studies, they assessed this validity criterion using the same group of individuals. They conducted annual assessments of 78 people with Alzheimer's disease and followed them up until they died, up to nine years later. NART scores were found to decline as dementia severity increased. The amount of NART decline was found to be a function of a person's previous MMSE

score, with lower MMSE scores predicting larger amounts of subsequent NART decline. This suggests that the NART may be sensitive to current cognitive functioning, and is not solely measuring pre-morbid abilities.

Interestingly there was an exception to these findings with one participant producing stable NART scores throughout, despite a decline in MMSE. Cockburn et al., (2000) concluded that relying on group data may be misleading and suggested there is more to learn about how dementia affects reading ability.

Overall, while the NART appears to overestimate the current abilities of people with dementia, performance has been shown to be affected by dementia severity, with lower scores being produced for people with more severe dementia.

Short NART

Following criticism that the full NART may be distressing to people who performed badly, it was suggested that the NART could be estimated on the basis of the first half of the test alone (Beardsall & Brayne, 1990; Crawford, Parker, Allan, Jack & Morrison, 1991). Bucks et al., (1996) aimed to validate this with a group of 119 people with dementia and 83 controls. The authors stated that there were unacceptably large discrepancies between the scores of the two versions of the NART and subsequently the short NART was deemed not to be valid as a replacement for the full NART. A criticism of Bucks at al., (1996) is that it was the only study which did not assess any of the suggested validity criteria. More research is needed to assess the validity of the short NART in terms of its correlation with current measures of ability.

Beardsall and Huppert (1997) which assessed only one the validity criteria, found no significant differences between the dementia group (n=20) and the control group

of average reading ability (n=30), on the short NART, CCRT and STW. However, the short NART led to a lower estimate of reading ability than the short CCRT, mean of 2.3 fewer words for the controls, and 3.8 for the dementia group. This suggests that the CCRT is superior to the NART, but further work is needed to see if a higher score on the CCRT equates to a better prediction of pre-morbid IQ.

From the papers reviewed, there is little to support the validity of the short NART, as other measures can provide a fairer estimate of PMIF.

Demographic Variables

Whilst demographic variables are completely independent of current functioning, Crawford et al. (1989b) have shown that they are not able to explain as much of the variance in WAIS Full-Scale IQ as the NART. It is therefore not clear how valid demographic variables are.

McFarlane et al. (2006) found demographic variables (based on Crawford and Allan's (1997) regression equation) to be a better estimate of pre-morbid functioning than the NART, in people with 'mild' dementia (MMSE score 14-23). Likewise Taylor (1999) supported the use of demographic variables. In a study of 84 people with dementia Taylor found that NART performance is affected by dementia severity as it correlated significantly with tests of current cognitive ability. He concluded that the NART was not valid as a measure and instead he advocated the use of demographics which are not affected by dementia severity.

As previously reported, Bright et al., (2002) found that demographics variables demonstrated lower correlations with current WAIS ability in the control group than the NART. As such they found that the NART was a better predictor of pre-morbid functioning. However, the authors noted that performance on the NART may

deteriorate if a more advanced dementia population was used; whereas estimates from demographic variables would not be affected.

Paolo et al., (1997) which assessed three of the validity criterion, found that Barona demographics accurately predicted short WAIS-R IQ's in the control group (n=44), and overestimated short WAIS-R IQ's in the dementia group (n=44). The Barona demographics could detect deterioration in more people diagnosed with mild impairment (DRS $\geq$ 110) than the NART. They concluded that demographic variables may be more powerful in detecting decline.

Uncertainty remains about the validity of demographic variables. Despite lower correlations with current abilities, demographic variables may be preferable in situations where other measures are compromised, such as with people with severe dementia; although, by this stage the dementia would probably be evident without the need for neuropsychological assessments.

CCRT

The NART assumes that words which are not pronounced correctly are not in a person's reading vocabulary. However, Beardsall and Huppert (1994) suspected that some people mispronounced words which they read accurately in everyday life. They suggested that words needed to be placed into context in order to facilitate recognition, so they developed the CCRT. Franzen et al.'s (1997) concluded that whilst people produced fewer pronunciation errors on the CCRT than the NART, work was needed to see whether or not this made the CCRT a better predictor of pre-morbid IQ.

The present review identified four studies that have investigated the validity of the CCRT. As already stated Beardsall and Huppert (1997) found that the short CCRT

provided a higher estimate of pre-morbid functioning than the short NART, in people with both minimal and mild/moderate dementia. Conway and O'Carroll (1997) supported this by comparing the scores of 30 people with Alzheimer's disease on both the NART and the CCRT. They found that people made significantly fewer errors on the CCRT than the NART (t=3.08, $p<0.01$), with the more severe dementia group (MMSE < 17) showing a greater increase in scores (2.6 fewer errors), than the group with an MMSE ≥ 17 (0.9 fewer errors). Moreover, the authors found that whilst the NART was correlated to MMSE scores, the CCRT was not. This suggests that performance on the CCRT is affected less by dementia severity than the NART.

Law and O'Carroll (1998) compared the scores of 21 people with Alzheimer's to 114 controls on the NART, CCRT and STW. They found performance on all three measures were relatively unaffected by Alzheimer's disease. People in the dementia group scored 4.4 words higher on average on the CCRT than the NART. Moreover, in the control group, the CCRT was shown to have a higher correlation (r=0.63) with measures of current intellectual abilities than either the NART (r=0.55) or the STW (r=0.36). From this they concluded that the CCRT was the fairest estimate of pre-morbid ability.

McFarlane et al. (2006) showed that performance on the CCRT was affected by dementia severity. They found that despite scoring higher on the CCRT than the NART, people with mild dementia (MMSE: 14-23) made significantly more errors than either the minimal dementia (MMSE: 24-28) or the control group.

A criticism of these studies is the size of the dementia groups. The largest study, McFarlane et al. (2006), used a sample of 66 people, however, this sample was

reported to be underpowered. If any of the other studies were also underpowered then this could have a significant impact on the conclusions made, and replications with larger populations are needed.

The finding that the CCRT correlates more highly with current ability in the control group, suggests that the CCRT is a better estimate of pre-morbid IQ than the NART. However, none of these studies assessed the correlation between the CCRT and either: scores taken prior to the onset of dementia, or current abilities in the dementia group. These criteria need to be assessed in order to determine the full validity of the CCRT.

WTAR

Despite its popularity among clinicians, only McFarlane et al., (2006) evaluated the validity of the WTAR. No differences between the controls and combined minimal and mild dementia group were found on the WTAR, $t(95)=1.71$, $p>0.05$, although there were significant differences between the minimal (MMSE: 24-28) and mild (MMSE: 14-23) dementia groups $t(65)=2.21$, $p<0.05$. This suggests that people make significantly more errors on the WTAR as dementia severity increases. As such the WTAR may only be valid with people with minimal dementia; however, further research is needed to confirm this. Moreover, there is a need to assess the validity of the WTAR in terms of its correlation with current intellectual ability, something that McFarlane et al. did not assess.

STW

Beardsall and Huppert (1997) found no significant differences between the dementia and control groups on the short STW, a test of lexical-decision-making. However, the authors noted that the probability was of borderline significance

(F=3.0, $p<0.06$), with people with more severe dementia: mild/moderate, (as defined by the Cambridge Mental Disorders of the Elderly Examination, CAMDEX; Roth et al., 1986), performing significantly worse than controls. They therefore suggested that the short STW is not valid as a predictor of pre-morbid IQ in people with mild/moderate dementia. Given that Baddeley et al. (1993) found the correlation between the short and full STW was 0.94, Beardsall and Huppert's (1997) findings can be generalised to the full STW. A limitation of this study is that the probability level is set at 0.06, which increases the chances of making a type 1 error. Moreover, as only 7 people had mild/moderate dementia, this study may be underpowered and replications are needed.

McFarlane et al. (2006) found that there were no significant differences between the controls and the combined minimal and mild dementia group on the STW, t(95)=0.61, $p>0.05$. They also found no significant differences between the mild (MMSE: 14-23) and minimal dementia (MMSE: 24-28) groups t(65)=1.11, $p>0.05$. They concluded that the STW is valid with all levels of dementia severity and may provide the best estimate of PMIF in people with mild dementia. However, they note the need to further investigate the correlation between the STW and current intellectual ability, something which Law and O'Carroll (1998) found to be low (r=0.36).

The evidence suggests that the STW may be useful as an estimate of pre-morbid IQ but further studies are needed to support this. It is noted, however, that McFarlane used a later version of the STW and further research is needed to explore whether this makes a difference to the findings stated.

Pre-Morbid Memory

Most of the methods of estimating PMIF, described above, focus on measuring a person's pre-morbid IQ. However, cognitive decline encompasses impairment in a person's memory abilities too. Given that pre-morbid IQ is often predicted on the basis of verbal IQ alone, memory abilities are being ignored. Currently, pre-morbid memory is measured by clinical judgement on the basis of demographics alone, but this is liable to considerable error. A need to develop objective measures of pre-morbid memory is indicated.

Hilsabeck & Sutker (2009) suggested the use of an implicit memory task, the Anagrams Solutions, as an objective way of measuring pre-morbid memory. However, they found that it was not valid as a measure of memory function, as it did not correlate significantly with explicit memory measures in the control group.

Duff, Chelune and Dennett (2011) evaluated the use of formulae (based on demographic variables and an estimate of pre-morbid intellect; Duff, 2010), to estimate pre-morbid memory in 1,059 Dementia clinic referrals. The pre-morbid memory equations significantly overestimated current abilities on four different measures. However, the memory formulae were found to correlate to MMSE scores, suggesting that they are affected by dementia severity. As such their validity is uncertain.

A critique of this study is that formal dementia diagnoses were not stated, with cognitive impairment seemingly implied from either MMSE or DRS. Thirty percent of participants scored 28 or higher on the MMSE, and consequently may not have had any cognitive decline. Replications of these findings using a confirmed dementia population are needed. Moreover, there is a need to explore the formulae's

validity across different levels of dementia severity, and when compared to a control group. These criteria need to be assessed before making conclusions as to the validity of this measure.

Limitations

Classification of Severity

There is little consistency in the way that dementia severity is defined: seven studies used the MMSE, one used the DRS, one the CAMDEX and three did not comment. The same is true for severity terminology. McFarlane et al. (2006) classed people as having 'minimal' dementia if they had an MMSE score between 24 and 28, and 'mild' between 14 and 23. Duff et al., (2011) classed people as 'milder' with an average MMSE of 24.5, whereas, Law and O'Carroll (1998), accepted people in the control group with an MMSE score of 25. Standardisation of severity terms are needed in order to fully integrate the research into clinical practice. Without this it will be difficult to determine how valid these measures of PMIF are with people with varying levels of dementia.

MMSE

MMSE scores are affected by variables such as age and education (Anthony, LeResche, Niaz, Von Korff & Folstein, 1982; Crum, Anthony, Bassett, & Folstein, 1993) so need to be adjusted accordingly. However, of the seven studies that used the MMSE, only McGurn et al., (2004) and Hilsabeck & Sutker (2009) explicitly noted the use of adjusted MMSE scores (the former for age 11 IQ and the latter for age and gender). This suggests that the other studies may be flawed if they classed severity on unadjusted MMSE scores.

Study	Exclusion criteria
Bucks, Scott, Pearsall & Ashworth (1996)	Not specified
Beardsall & Huppert (1997)	Depression
Paolo, Tröster, Ryan & Koller (1997)	Stroke, psychiatric disorder, significant head trauma, illicit drug or alcohol abuse, medication that impairs cognition and other signs/symptoms of neurological disorders that may compromise cognition
Conway & O'Carroll (1997)	Infective, metabolic, nutritional and hormonal causes of organic disorder were excluded as well as functional psychiatric disorders
Law & O'Carroll (1998)	Not specified
Taylor (1999)	History of alcohol abuse, uncorrected sight/hearing, physical disability affecting testing, recent infection or other illness, head injury, major psychiatric problems or ECT
Cockburn, Keene, Hope & Smith (2000)	Alcohol abuse, any suggestion of causes of disease other than dementia i.e. previous head injury or hypothyroidism

Bright, Jaldow & Kopelman (2002)	Hypertensive or cerebrovascular disease
McGurn et al. (2004)	Not specified
McFarlane, Welch & Rodgers (2006)	Alcohol abuse, depression, stroke, head injury and any uncorrected eyesight problems
Hilsabeck & Sutker (2009)	Current or past neurological or psychiatric illness, history of significant head trauma, active substance abuse or dependence or cognitive impairment so severe as to prohibit participation in the study
Duff, Chelune & Dennett (2011)	Not specified

Table Three: Exclusion Criteria

Causes of Cognitive Decline

Several factors can cause cognitive decline other than dementia. These include: age (Morris, Craik & Gick, 1990), psychosis (Bilder et al., 2000; Addington et al., 2003); substance misuse (Block & Ghoneim, 1993); excessive alcohol (Evert & Oscar-Berman, 1995); prescribed medications (Fox et al., 2011); acquired brain injury (Whyte, Skidmore, Aizenstein, Ricker & Butters, 2011) and stroke (Mok et al., 2004). However, very few studies screened for these factors (see Table Three). There may be potential confounds in any research, which assumes cognitive decline to be produced by dementia alone.

Dyslexia

Several measures require a person to read irregular words. However, this may result in an underestimation of pre-morbid functioning in some people with dyslexia, if they rely on phonetics to help them to read. Indeed the NART states that it is not valid with people with dyslexia. The STW, however, is cited as being valid for use with dyslexia (Baddeley at al., 1993) although its validity with a dementia population still needs to be proven. Newer non-reading estimates, such as Spot-the-book and Spot-the-country (Scott, Wit & Deary, 2006), have also shown promise in healthy participants, but further assessment with participants with both dyslexia and dementia is needed.

Demographic Equations

Throughout this paper demographic variables have been explored as one group. However, demographic estimates are derived from several different regression equations (Crawford et al., 1989a; Barona et al., 1984; Crawford & Allan, 1997). It

would be interesting to know if there are significant differences between these equations, and if so, which is the most valid with dementia.

Diagnostic Criteria

There is considerable variation in how dementia is classified. The NINDS-ADRDA (McKhann et al., 1984) referring specifically to Alzheimer's disease, was referred to in six studies; the CAMDEX and DSM-IV were both used in two studies, while ICD-10 (World Health Organisation, 1992), the Hachinski Index (Hachinski et al., 1975) and DSM-III-R (American Psychiatric Association, 1987) were all referred to once (one study used two criteria). Choice of diagnostic criteria seems varied. A study by Wetterling, Kanitz & Borgis (1996) on vascular dementia found a concordance rate of only 53% between the diagnostic criteria used. Research is needed to clarify whether diagnostic variations in the literature reviewed in this present paper have any impact on the findings stated.

CLINICAL IMPLICATIONS

The present review evaluated the validity of measures of pre-morbid intellectual functioning with dementia. No evidence was found supporting the validity of one single measure for use with dementia at all stages of severity. Moreover, a number of measures should not be used in particular situations. Both the NART and the WTAR are shown to underestimate the ability of people with an MMSE less than 24. Whilst the CCRT produced higher estimates of pre-morbid reading ability, it too is affected by dementia, and may be unreliable with people with an MMSE less than 24. There was no evidence to support the use of the short NART as a valid estimator, and this should be avoided where possible. This is also true for the Anagram Solutions, whose use was not validated.

In terms of tests that should be used by clinicians, the current evidence suggests that the CCRT is the most valid measure in people with minimal dementia (MMSE ≥ 24). It correlates well with current abilities in the control group, and produced an estimate of reading ability up to 4.4 words higher than the NART. In the dementia group, it was also shown not to correlate with current measures of ability.

There is more debate, however, as to which measure to use with people with more severe dementia (MMSE<24). Given that several measures are affected by dementia severity, underestimation of ability may occur if these measures are used with people with more severe dementia. At present it is advised that demographic variables, which are not affected by dementia severity, are the best predictors of pre-morbid ability at this level of severity.

The Spot-the-Word test has some promising results across all levels of dementia severity but the evidence base for this is limited. However, one study questioned its correlation to current measures of ability in controls. Given that this could potentially be valid for both people with mild dementia and people with dyslexia, there is a need to investigate this further.

Furthermore, ceiling effects in measures must always be acknowledged. The highest possible pre-morbid IQ estimated on the WTAR is 119. Therefore estimated IQ's should be considered as a lower estimate of ability, and not an absolute value.

Clinicians are advised to make use of multiple measures in order to estimate pre-morbid ability. Scores gained from at least two distinct measures should be cross-checked against each other. Large discrepancies will highlight potential limitations in the measures, and alert clinicians to a possible underestimation of ability. Consequently this should help to reduce the number of clinical errors made.

Conclusions

Currently available objective measures of pre-morbid ability, used in addition to clinical judgement, should reduce the chance of clinical misdiagnosis. The CCRT is suggested as the best available measure of PMIF for people with MMSE scores of 24 or more, while demographic variables are recommended for scores below 24. It is suggested that a combination of measures may be best to ensure an accurate estimate of PMIF. Finally, a consistent definition of dementia severity is needed, against which to compare the validity of different measures of pre-morbid intellectual functioning.

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Chapter 2: Empirical Paper

Diagnosis of Dementia and Relative Cognitive Decline

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ABSTRACT

Objectives

The present study explores whether there is a relationship between estimated pre-morbid intellectual functioning and the amount of cognitive decline shown prior to receiving a diagnosis of dementia.

Methods

A retrospective design was adopted which collected data including estimated pre-morbid IQ and RBANS scores from memory clinic patients' files. This was used to calculate the amount of cognitive decline that people undergo prior to having an assessment for dementia. Correlational analyses were carried out comparing the amount of cognitive decline and pre-morbid intellectual functioning.

Results

Of the population sampled, 135 patients had been diagnosed with dementia; 59 with mild cognitive impairment and 51 showed no cognitive impairment. A positive relationship was found for all groups between pre-morbid intellectual functioning and amount of cognitive decline. As a person's estimated pre-morbid functioning increased so too did the amount of cognitive decline that they experienced. A multinomial logistic regression highlighted age and RBANS score as being the most predictive of diagnostic classification. This model accounted for up to 53.8% of the variance.

Conclusions

Pre-morbidly high functioning people experience greater amounts of cognitive decline prior to being given a diagnosis of dementia than other people. This provides support for an ascertainment bias in the dementia assessment. Changes to the current dementia assessment process are indicated, which take into account the amount of cognitive decline experienced.

KEY WORDS: Dementia; Education; Pre-morbid Intellectual Functioning; Ascertainment Bias.

Diagnosis of Dementia and Relative Cognitive Decline

INTRODUCTION

Currently, there are over 800,000 people with dementia in the United Kingdom (Alzheimer's Society, 2012) and this figure is set to double in the next thirty years as the population ages (Knapp et al., 2007). However, it is estimated that only 40% of people with dementia receive a diagnosis (Alzheimer's Society, 2011).

Living Well with Dementia: The National Dementia Strategy for England (Department of Health, 2009) states that significant improvements need to be made to dementia services in terms of improved access to services, earlier diagnosis and intervention, and higher quality of care. An earlier diagnosis may improve the quality of people's lives by allowing people additional time to make legal and financial decisions about their future. People with Alzheimer's disease may receive medication at an earlier stage, which can help to slow the progression of the disease. They may also be taught psychological strategies to help them to maximise the cognitive skills that they do have. It is therefore important to determine how people with dementia can be identified as early as possible.

There is much debate as to the influence that education, and by association pre-morbid intellectual functioning has on dementia. Many studies show that education is inversely related to dementia such that people with less education are more likely to be diagnosed (the Canadian Study of Health and Aging, 1994; Dartigues et al., 1991; De Ronchi et al., 1998; Fratiglioni and Wang, 2007; Gatz et al., 2007; Hill et al., 1993; Ngandu et al., 2007; Ott et al., 1995; Prencipe et al., 1996; Schmand, et al., 1997 and Zhang et al., 1990). Paradoxically, however, people who were pre-morbidly high functioning have been shown to deteriorate at a much faster rate after

being diagnosed with dementia, than those who were pre-morbidly low functioning (Hall et al., 2007 and Stern, 2006).

Conversely, there are studies which found no evidence that less education is a risk factor for diagnosis of dementia (Beard, Kokmen, Offord & Kurland, 1992; Bonaiuto et al., 1995; Bowler, Munos, Merskey & Hachinski, 1998 & O'Connor, Pollitt & Treasure, 1991). Yet others that suggest that once diagnosed, pre-morbidly high functioning people decline at the same rate as everybody else (Del Ser, Hachinski, Merskey & Munoz, 1999).

One explanation that has been put forward to account for why dementia is diagnosed less frequently in people with higher levels of education attributes this to the presence of greater *cognitive reserve* in individuals with a higher level of estimated pre-morbid intellectual functioning. Cognitive reserve describes the mind's resilience to neurological brain damage (Stern, 2002). Autopsy studies have shown that some people experience considerable amounts of brain damage, but exhibit little clinical manifestation of dementia itself (Katzman, 1988). This phenomenon was found to apply mainly to people whose brains contained a greater number of neurons than average and weighed more. Therefore when disease processes began to cause damage to the brain, high-functioning individuals did not exhibit any signs of the condition, as they effectively had a reserve of neurons. As several studies have shown that individuals with higher IQ's and/or greater cognitive stimulation have larger brain volumes (Kesler, Adams, Blasey & Bigler, 2003 and Willerman, Schultz, Rutledge & Bigler, 1991), it is suggested that these people also have a higher reserve. Ince (2001) provided support for cognitive reserve. He found that 25% of people who met the pathological criteria for

Alzheimer's at autopsy, had previously unimpaired neuropsychological assessments, on average 1.2 years before they died. Additional findings for brain reserve have been provided by: Fratiglioni & Wang (2007); Roselli et al., (2009); Stern, (2009) and Valenzuela (2008).

An alternative explanation of why people who are high-functioning are diagnosed with dementia less frequently, is that there is an *ascertainment bias* in the way that dementia is diagnosed. This explanation is supported by Tuokko, Garrett, McDowell, Silverberg & Kristjansson, (2003). These authors criticise the use of criteria for assessing dementia which are based on an *absolute* threshold approach (e.g. such as the MMSE cut-off score of 24, suggested in the National Institute for Health and Clinical Excellence guidelines; NICE, 2006), and instead advocate the need to establish *relative* cognitive decline within each individual (Bain, 2006). The ascertainment bias model assumes that pre-morbidly high functioning individuals must experience greater amounts of cognitive decline in order to reach that absolute threshold and receive a diagnosis.

Support for the ascertainment bias is provided by findings that tests of cognitive functioning are influenced by a person's education and intelligence (Christensen and Jorm, 1992). As a result higher cut-off points on tests of cognitive functioning should be used when assessing pre-morbidly high-functioning people with dementia (Starr and Lonie, 2007). Moreover, when test scores are adjusted on the basis of pre-morbid intellectual functioning, studies show that more people can be detected as having dementia at an earlier stage (Lindeboon, Launer, Schmand, Hooyer & Jonker, 1996; Rentz et al., 2004).

Autopsy studies, which are able to confirm previously probable diagnosis of Alzheimer's disease, have provided further support to the ascertainment bias theory. Munoz, Ganapathy, Eliasziw and Hachinski (2000) found that there were no significant differences in terms of educational attainment between a group of people who had autopsy-confirmed Alzheimer's disease and a control group who did not. This suggests that high education may not be as much of a protective factor for the development of dementia as originally believed.

The presence of an ascertainment bias may account for the discrepancies in the literature as to whether or not educational attainment is inversely proportional to dementia. If people are diagnosed on the basis of absolute amounts of cognitive decline, rather than relative amounts, this may prevent people with a high level of education from gaining a diagnosis of dementia. Consequently, people with high education will appear to be less susceptible to dementia, as they have not gained a diagnosis. This study aims to move the literature forward by exploring this further.

Aims

Main Aim: To explore whether there is a relationship between people's estimated pre-morbid levels of intellectual functioning, and the amount of cognitive decline shown before being diagnosed with dementia.

Hypothesis: It is hypothesised that in those individuals diagnosed with dementia, a greater amount of cognitive decline will be shown at the point of diagnosis in individuals with higher pre-morbid intellectual functioning, compared to individuals with lower pre-morbid levels of intellectual functioning.

Subsidiary Aim: To explore which variables, including clinical (cognitive) and demographic variables, are the most predictive of variance within the diagnostic process.

METHODS

Design

The present study uses a quantitative retrospective design. Patients were divided into three groups on the basis of their diagnosis: Dementia, Mild Cognitive Impairment (MCI) and No Cognitive Impairment (NoCI).

A correlational design was used to explore the relationship between estimated pre-morbid IQ and the amount of cognitive decline shown before receiving a diagnosis of dementia. A multinomial logistic regression was used to explore which variables contributed significantly to a model predicting diagnostic group allocation.

Participants

The sample for the present study was obtained from people who had previously attended an NHS memory clinic and had been assessed for dementia. People who met the relevant criteria (see below) were included in the study.

Measures

Wechsler Test of Adult Reading (WTAR).

The Wechsler Test of Adult Reading (WTAR; Wechsler, 2001) (Appendix 8) is used to estimate a person's pre-morbid IQ. It consists of 50 phonetically irregular words that require prior knowledge of them in order to pronounce them correctly. The test was standardised on a sample of 331 British people and 1134 Americans, aged between 16-80 years old. The WTAR shows good internal consistency, with coefficients ranging from 0.87 to 0.95, and good test-retest reliability (r=0.90)

(Wechsler, 2001). The test shows good convergent validity with other reading tests, such as the American National Adult Reading Test (AMNART; *r*=0.90) and correlates highly with measures of intelligence, specifically the Wechsler Adult Intelligence Scale (WAIS-III) Full-Scale IQ, (*r*=0.73) (Wechsler, 2001).

Repeatable Battery for the Assessment of Neuropsychological Status (RBANS).

The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, 1998) contains 12 subtests which measure a person's attention, language, visuospatial/constructional abilities, immediate and delayed memory. It was designed for use with English-speaking adults aged between 20 and 89 years and has normative scores derived from a sample of 540 healthy adults (Randolph, 1998).

The RBANS indices have been shown to have high correlation coefficients when measured against other neuropsychological measures. The language index, for example, correlated highly with the Boston Naming Task, (*r*=0.75) and the Visuospatial/Constructional index correlated highly with the Rey-Osterrieth Complex Figure Test (*r*=0.79; Randolph, 1998). The RBANS has been shown to have good test-retest reliability across the two versions of the test, with a correlation coefficient of 0.84 (Wilk et al., 2004).

Mini-Mental State Examination (MMSE).

The Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) (Appendix 9) is a basic measure of a person's cognitive abilities. The test has been shown to have good test-retest reliability over both 24 hours (*r*=0.89) and 28 day intervals (*r*=0.98), and good inter-rater reliability (*r*=0.83) (Folstein et al., 1975). It

was able to distinguish between people with and without cognitive impairment, when tested on a group of 137 people (Folstein et al., 1975). It also correlated strongly with the Wechsler Adult Intelligence Scale (WAIS) verbal (r=0.78) and performance scales (r=0.66).

Procedure

Following ethical approval data was collected from patients' memory clinic files. All data was taken from the point of initial contact with the memory clinic, regardless of whether subsequent assessments were carried out. Data consisted of demographic details (age, gender and ethnicity); level of education (see Appendix 10 for coding); estimated pre-morbid IQ (measured by the WTAR); total RBANS score; MMSE score and diagnostic outcome (as stated by the Psychiatrist involved in the memory clinic). Data pertaining to the exclusion criteria (see below) were also extracted, including the presence of a severe and enduring mental health problem and excessive alcohol use.

Closed patient files.

Permission to access the files of patients who have been discharged from the service, closed files, was obtained from the National Information Governance Board for Health and Social Care (NIGB), for support under section 251 of the National Health Service Act (2006) to process patient information without consent. Permission was also sought from the Black Country Research and Ethics

Committee, the Research and Development Committee for the relevant NHS Trust[3] and from the lead clinicians involved in each of the memory clinics.

Open patient files.

In addition, information was collected from the files of patients who were still accessing the memory clinic service. Written consent was obtained from these individuals prior to accessing their files (Appendices 11-12).

Inclusion Criteria

For patient data to be included in the study, each patient file needed to have:

- A valid estimate of pre-morbid IQ as measured by the WTAR
- An RBANS total score
- A diagnostic outcome

Exclusion Criteria

Patient data was excluded from the study if patients had subtypes of dementia other than Alzheimer's disease, Vascular or Mixed Dementia. Patients' data was also excluded if patients had severe and enduring mental health problems, such as schizophrenia, psychosis or bipolar disorder, as these conditions have been shown to affect a person's cognitive abilities (Schouws et al., 2009; Wood et al., 2007; O'Carroll, 2000). If alcohol use was considered to be a factor in a patient's presentation, then their data was also excluded.

[3] To protect patient confidentiality, the location of the memory clinics will remain anonymous. This includes the name of the NHS Trust where the memory clinics were based.

In order to access the minimum amount of information necessary, the data of patients who had previously accessed secondary or tertiary mental health services at the memory clinic location were excluded.

Data Analysis

Data was analysed using the Predictive Analytics SoftWare (PASW) version 17. For the purposes of analysis, the raw scores were converted into z-scores in order to make them comparable (see appendix 13 for z-score calculation). Cognitive decline was calculated by subtracting a person's total RBANS z-score, from their estimated pre-morbid IQ z-score.

A correlational analysis was carried out in order to compare estimated pre-morbid IQ and the amount of cognitive decline shown prior to diagnosis. This was done for each of the three diagnostic levels.

A multinomial logistic regression was conducted in order to explore which variables had a significant impact on the way that patients were assigned to a diagnostic category.

RESULTS

The data from 245 memory clinic patients were included in the analysis. The data was collected from four memory clinic sites and pertained to memory clinic assessments carried out between 2006 and the time of the study. The dementia group consisted of 135 patients comprising: 77 people with Alzheimer's disease, 28 with vascular dementia and 30 with mixed dementia. There were 59 patients in the Mild Cognitive Impairment (MCI) group and 51 in the No Cognitive Impairment (NoCI) group. Table 1 shows demographic details; the highest level of education achieved and the average scores for each of the groups.

An Analysis of Variance (ANOVA) showed no significant differences between the groups in terms of gender, ethnicity, or estimated pre-morbid IQ ($F<1$). There was a significant difference between the groups in terms of the age of the patients $F(2,242)= 42.48$, $p<0.001$, with the dementia patients being significantly older than the other two groups. There was also a significant difference in education, $F(2,240)= 4.16$, $p=0.02$, with patients in the dementia group receiving fewer years of education overall.

		Dementia (N=135)	MCI (N=59)	No CI (N=51)
Age		77.3 sd = 8.06 (55-98)*	71.69 sd = 9.20 (45-92)	63.35 sd = 12.15 (42-88)
Gender (%)		Female: 48 Male: 52	Female: 39 Male: 61	Female: 45 Male: 55
Ethnicity (%)		White: 97.8 Asian: 0.7 Black: 0.7 Arabic: 0.7	White: 96.6 Asian: 3.4	White: 92.2 Asian: 5.9 Black: 1.9
Education: Number of patients (%)	**School Education**	103 (76.3)	39 (66.1)	31 (60.8)
	Further Education	18 (13.3)	11 (18.6)	12 (23.5)
	Higher Education	12 (8.9)	6 (10.2)	6 (11.8)
	Masters	1 (0.7)	1 (1.7)	2 (3.9)
	Data unavailable	1 (0.7)	1 (1.7)	0
MMSE		24.44 sd = 3.83 (10-30)	27.88 sd = 1.58 (24-30)	27.70 sd = 3.25 (14-30)
Pre-morbid IQ		101.49 sd = 10.51 (70-122)	100.97 sd = 10.47 (71-118)	104.10 sd = 9.07 (82-123)
RBANS Score		65.93 sd = 12.27 (47-107)	81.37 sd = 14.02 (53-113)	93.43 sd = 15.34 (49-122)
Cognitive Decline (Z-score)		0.50 sd = 1.01 (-3.05 – 2.64)	-0.44 sd = 1.19 (-2.97 – 1.49)	-0.82 sd = 0.71 (-2.09 – 0.95)

**The Range is provided in brackets, unless otherwise stated.*

Table 1: Demographic Variables, Education and Mean Scores.

Correlations

A significant positive Pearson's correlation coefficient was found between estimated pre-morbid IQ and amount of cognitive decline, in all three of the diagnostic groups: Dementia group, $r(134)=0.761$, $p<0.001$; MCI group, $r(58)=0.745$, $p<0.001$ and NoCI group, $r(50)=0.409$, $p=0.003$. The correlation was strongest in the dementia group and weakest, but still significant, in the no cognitive impairment group. Therefore the higher a person's estimated pre-morbid IQ, the greater the amount of cognitive decline they experienced prior to receiving a diagnosis of dementia.

Correlation coefficients were contrasted to determine whether the magnitude of the relationships found for the three groups were significantly different. The strength of the correlation coefficient did not alter significantly between the Dementia and MCI groups, z=0.23, $p=0.82$. However, the NoCI group correlation was significantly lower than either of the other groups: Dementia and NoCI, z=3.35, $p=0.001$ and the MCI and NoCI groups, z=2.68, $p=0.007$.

According to the guidelines suggested by Cohen (1988), both the Dementia and the MCI group had a large effect size and the NoCI group had a medium effect size. Scatter plots for the three groups are shown in Appendices 14 to 16.

Power calculations were carried out in order to ascertain how many patient datasets would be needed to replicate the findings from the present study. For an 80% chance of the relationship being significant at the 0.05 level, 15 people would be needed for the dementia group; 16 people for the MCI group and 48 people for the NoCI group. This suggests that the sample sizes used in the present study were sufficient to detect an effect occurring.

A post-hoc analysis was conducted to further explore the mean cognitive decline for people with different levels of estimated pre-morbid IQ (Table 2).

Diagnosis	Intelligence* Classification	N	Pre-morbid IQ	RBANS	Cognitive Decline (z-score)
Dementia	Low Average/ Borderline	17	83.76 sd = 6.17	57.18 sd = 7.70	-0.73 sd = 0.90
	Average	83	99.64 sd = 5.33	65.11 sd = 11.05	0.37 sd = 0.74
	High Average/ Superior	35	114.49 sd = 3.16	72.11 sd = 13.84	1.42 sd = 0.80
MCI	Low Average/ Borderline	6	78.67 sd = 6.35	71.33 sd = 7.69	-2.04 sd = 0.72
	Average	42	100.74 sd = 5.46	83.02 sd = 15.27	-0.55 sd = 1.01
	High Average/ Superior	11	114.00 sd = 2.68	80.55 sd = 9.00	0.88 sd = 0.48
NoCI	Low Average/ Borderline	2	84.50 sd = 3.54	63.50 sd = 12.02	- 1.02 sd = 0.34
	Average	33	100.39 sd = 5.51	90.49 sd = 14.15	- 1.01 sd = 0.70
	High Average/ Superior	16	114.19 sd = 4.29	103.25 sd = 10.32	- 0.40 sd = 0.60

** People were grouped into three levels of estimated pre-morbid IQ, this was based on Wechsler's intelligence classifications (Wechsler, 1997). Low Average/Borderline = Estimated Pre-morbid IQ of 70-89; Average = 90-109; High Average/Superior = 110-119 (highest score possible on WTAR).*

Table 2: Mean Cognitive Decline Experienced by Different Intelligence Classifications.

Prediction of Diagnostic Category

A multinomial logistic regression was conducted to predict diagnostic group allocation. Demographic variables (age, gender, ethnicity and education); scores from the RBANS and MMSE; estimated pre-morbid IQ and amount of cognitive decline were used as the predictor variables.

An alpha level of 0.05 was set for inclusion of variables remaining in the model. Age, MMSE score and RBANS total were all found to be significant predictor variables. However, it was clear that multicollinearity was an issue between MMSE and RBANS score; they had a highly significant correlation, r=0.603, $p<0.001$. Given that RBANS score was found to have a higher correlation (r=0.643) with diagnostic group than the MMSE (r=0.402), this variable was chosen to remain in the model and MMSE score was removed. Gender, ethnicity, education, estimated pre-morbid IQ and amount of cognitive decline did not contribute significantly to the diagnostic outcome and were removed from the model.

A test of the full model (age and RBANS score) against a constant only model was statistically significant, indicating that the predictor variables as a set reliably distinguished between the diagnostic classifications ($\chi^2(4)=153.204$, $p<0.001$). The model accounted for between 46.5% and 53.8% of the variance (Cox and Snell's and Nagelkerke's Pseudo R^2 respectively). The model was able to predict diagnostic group allocation with a 69.0% success rate overall, with the dementia group being predicted the best (see Table 3). The classification accuracy surpassed the 'by chance' accuracy criteria, supporting the utility of the model.

	Predicted Classification			
Actual Classification	Dementia	MCI	NoCI	Correct (%)
Dementia	121	9	5	89.6
MCI	33	15	11	25.4
NoCI	6	12	33	64.7
Overall Percentage (%)	65.3	14.7	20.0	69.0

Table 3: Model's Ability to Predict Diagnostic Group Allocation

In the dementia group both Age, b=0.129, Wald $\chi^2(1)$=25.773, $p<0.001$ and RBANS, b= -0.128, Wald $\chi^2(1)$= 48.867, $p<0.001$ significantly predicted diagnostic group allocation between the dementia and NoCI groups.

Age and RBANS score also significantly predicted diagnostic group allocation between the MCI and NoCI groups: Age, b=0.062, Wald $\chi^2(1)$=8.992, $p=0.003$, and RBANS score, b= -0.049, Wald $\chi^2(1)$=10.512, $p=0.001$.

			95% Confidence Interval for Odds Ratio	
		Odds Ratio	Lower	Upper
Dementia vs. NoCI	Age	1.14	1.08	1.20
	RBANS	.88	.85	.91
MCI vs. NoCI	Age	1.06	1.02	1.11
	RBANS	.95	.92	.98

Table 4: Odds Ratios

Table 4 shows the Odds Ratios (OR) for the variables. The Odds Ratios show the strength of association between a predictor and a response variable. For example, in the Dementia group, when a person's age increases by 1 year, the chances of a person being diagnosed with dementia increases by a factor of 1.14. Furthermore, as RBANS score increases by 1 point, the chances of a person being diagnosed with dementia increases by a factor of 0.88 (which equates to a 12% decrease in risk).

DISCUSSION

Correlational Analyses

The results show that the higher a person's estimated pre-morbid IQ is, the greater the amount of cognitive decline that they will show prior to being diagnosed with dementia.

These findings provide support for the presence of an ascertainment bias in the diagnostic process. The positive correlation between estimated pre-morbid intellectual functioning and the amount of cognitive decline, suggests that an absolute threshold level of impairment is currently being used to diagnose people. This would explain why people with high pre-morbid intellectual functioning show more cognitive decline prior to receiving a diagnosis, as their cognitive abilities must decrease by a larger amount before they reach the absolute threshold level. Conversely, people with lower pre-morbid intellectual functioning experience less cognitive decline prior to reaching the diagnostic threshold.

These findings cannot be explained by the presence of cognitive reserve. The Cognitive Reserve theory would suggest that cognitive reserve compensates for the presence of brain damage and prevents a person with high pre-morbid intellectual functioning from exhibiting signs of clinical or functional impairment. The finding of large amounts of cognitive decline prior to diagnosis in pre-morbidly high functioning people contradicts this theory.

Of particular note was the large amount of cognitive decline observed in patients who did not receive a diagnosis of dementia. In the MCI group, 16 people showed cognitive decline that was greater than the mean amount experienced by the dementia group, but were still classed as having mild cognitive impairment. Of

these 16 people, nine had an estimated pre-morbid IQ of 110 or over (the threshold used to denote high average intelligence in the WTAR). Two people experienced cognitive decline of almost three times the average of the dementia group. In the NoCI group a further three people experienced cognitive decline greater that the average amount of the dementia group; two of these people had an estimated pre-morbid IQ of 110 or over. The presence of an ascertainment bias in the assessment process is able to explain these observations. This theory suggests that some people with high estimated pre-morbid intellectual functioning are being incorrectly categorised as not having dementia. Despite showing large amounts of cognitive decline, their intellectual ability at the time of the assessment may still have been above the threshold needed for dementia diagnosis.

If people with high estimated pre-morbid abilities are being incorrectly diagnosed, then this would also account for the presence of a smaller, but still significant, correlation in both the Mild Cognitive Impairment and No Cognitive Impairment groups.

Prediction of Diagnostic Category

The results of the multinomial logistic regression show that out of all of the variables investigated in the present research, only three variables: Age, RBANS and MMSE score were able to predict diagnostic group allocation. Relative cognitive decline was not predictive of diagnostic category. Given that RBANS and MMSE scores were shown to be highly correlated, MMSE score was excluded from the model. From the use of only a person's age and their RBANS score, 89.6% of allocations into the dementia group could be correctly predicted.

The finding that relative amounts of cognitive decline were not predictive of diagnostic outcome provides further support for the presence of an ascertainment bias, especially since measures that were significant (RBANS and MMSE) were based on absolute threshold measures of cognitive decline. If diagnosis took into account people's previous levels of cognitive ability, then it would be expected that relative amounts of cognitive decline would have an impact on the diagnostic outcome that people receive. Instead, relative amounts of cognitive decline were not significant.

Clinical Implications

These findings have significant clinical implications for the way that people with high pre-morbid intellectual functioning are diagnosed with dementia. Based on the findings of the present study, it is suggested that high-functioning people who go on to develop dementia, must show a greater amount of cognitive decline before they receive a diagnosis of dementia. This will have consequences for such individuals in terms of accessing relevant healthcare provision.

The correlation between estimated pre-morbid IQ and amount of cognitive decline also has implications for pre-morbidly low functioning people. The lowest recorded estimated pre-morbid IQ in the no cognitive impairment group was 82 in comparison to 71 in the mild cognitive impairment group and 70 in the dementia group. It is possible that more people with lower estimated pre-morbid IQs are being diagnosed with dementia or mild cognitive impairment and fewer people are being labelled as having no cognitive impairment. Future research which segregates people into distinct groups on the basis of their estimated pre-morbid IQs may be needed to clarify this.

These findings bring a new perspective to studies such as Ince (2001) which found that 25% of people who met the criteria for Alzheimer's disease at autopsy had previously unimpaired neuropsychological assessments. Originally this was believed to provide further support for the cognitive reserve model, but it may also highlight the shortcomings of current neuropsychological assessments, which do not account for relative amounts of cognitive decline. If neuropsychological assessments cannot detect cognitive impairment in people with high pre-morbid functioning, this could explain the inverse relationship between education and dementia, as pre-morbidly high functioning people may fail to be diagnosed with dementia.

The presence of an ascertainment bias could also explain why some studies (such as Hall et al., 2007 and Stern, 2006) have suggested that people with high pre-morbid functioning decline at a faster rate when they are diagnosed with dementia. One explanation may be that because these individuals are being diagnosed at a much later stage, this may result in a much more rapid progression of the disease. As such their prognosis would be expected to be poorer.

Clinically, one area of concern is the recent changes to the way in which people are being assessed for dementia within the NHS. Since 2010 dementia nurses have been given more responsibility in assessing people for cognitive decline. However, they do not utilise any neuropsychological tests to evaluate a person's estimated pre-morbid IQ. The findings of this study highlight the importance of assessments taking account of relative cognitive decline. This is not possible unless a person's pre-morbid IQ is estimated.

Limitations

The WTAR was used to estimate pre-morbid functioning. However, there is debate as to how valid the WTAR is as a measure. It has a significant ceiling effect with the maximum possible estimated pre-morbid IQ being 119. It is therefore likely that the amount of cognitive decline reported here is an underestimate of the true amount, as some people may have started with scores significantly higher than 119. If there is a move to use relative decline in dementia diagnosis, this ceiling effect needs to be taken into account when interpreting neuropsychological assessments of pre-morbidly high functioning individuals.

As the present study was making use of the assessment processes currently used in memory clinics in the NHS, it was not possible to estimate pre-morbid IQ on the basis of demographic variables (Crawford et al. 1989). It had been intended that the WTAR estimated pre-morbid IQ would be cross-checked against an estimate produced from demographic variables. However, there was a lack of detail in some of the patients' medical files as to what occupation people had, so this was not possible. In future it may be an advantage to estimate pre-morbid intellectual functioning through a range of measures and not rely solely on pre-morbid estimation made by the WTAR.

The present study did not exclude people with depression. It is possible that this may have confounded some of the results, as cognitive abilities have been shown to be affected by depression (Austin, Mitchell & Goodwin, 2001; Goodwin, 1997). However, as depression may have been present in all groups, it should not have had a significant impact on overall findings. Future research should control for this.

A further limitation of the present study is the inclusion criteria for the No Cognitive Impairment group. This group was included in the study as it was thought that some people with dementia, who had high estimated pre-morbid intellectual functioning, may have been falsely classified as not having any cognitive impairment. In addition, this group was used as a control group in the regression model to which the other groups were compared. However, the fact that this group may have contained people with cognitive decline, even if they had not received a formal diagnosis, may affect its use as a reference group for the regression model. This could explain why the model was unable to account for more than 53.8% of variance. Replications of the regression analysis using people who have not experienced any cognitive decline are needed in order to confirm these results.

Future Research

There were a number of people whose cognitive abilities were re-assessed after twelve months in order to confirm their diagnosis. It is possible that a number of diagnoses were altered at this later time. This information was outside the remit of this study. However, it would be interesting to explore this further to see how much cognitive decline was shown prior to people gaining their final diagnosis.

While the present study indicates that people with high estimated pre-morbid functioning undergo greater cognitive decline prior to receiving a diagnosis of dementia, it does not explain why these people have already undergone greater amounts of decline at the point of accessing the memory clinic. Anecdotally, members of a dementia support group commented that they found it very difficult to access secondary services. Some people commented that they had to visit their

GP on several different occasions before their memory complaints were taken seriously. Therefore, some GP's may be acting as a barrier to diagnosis and may prevent people from accessing secondary services. Further research needs to be done to explore what protocols are used by GP's when seeing patients with subjective memory complaints.

The present study found a significant difference between the groups in terms of educational attainment, whereby the people in the dementia group had significantly fewer years of education than those in the other two groups. Now that an ascertainment bias has been highlighted, further research is awaited to explore whether an educational difference remains if people are diagnosed on the basis of relative amounts of cognitive decline and not absolute values. The findings of such research could have significant implications for the Cognitive Reserve theory.

Conclusion

The present study has shown that people with high estimated pre-morbid IQ show greater amounts of cognitive decline prior to receiving a diagnosis of dementia, than people with lower estimated pre-morbid IQ. The findings of the present study challenge the argument that cognitive reserve can adequately account for the inverse relationship between education and dementia diagnosis and instead suggest that there is an ascertainment bias at work. Further research with larger sample sizes is indicated to develop the evidence base for this finding. The idea that pre-morbidly high functioning people experience greater amounts of cognitive decline prior to diagnosis, highlights the need for changes in the dementia assessment process which takes into account relative amounts of cognitive decline.

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Chapter 3: Reflective Paper

Challenges in Accessing Retrospective Clinical Data for Research in the Field of Dementia: A Reflective Account

Word Count: 3,987 (excluding references)

Overview

In this paper I will reflect on the process of carrying out research in the field of dementia. The material for this paper is taken from my own experiences of the research process; observations that I have made along the way and my reflections on factors that influenced me to carry out research into dementia.

I will reflect on elements of the research that were difficult to overcome, notably that of accessing retrospective clinical data, and think of suggestions as to how to make this process easier for future researchers. Finally I will discuss areas for further research within the field of dementia.

Background and Interest in Dementia Research

Whilst on placement in an Older Adult Psychology service, I co-facilitated a memory group for both people with dementia and their carers. I learned a great deal about the experiences that people affected by dementia go through. Some individuals with dementia were much more aware about their symptoms than others, and despite being a group for people who were only just diagnosed, there were noticeable differences in the levels of severity of dementia witnessed. This made me curious to know why this was.

I was very moved by some of the stories shared in the group, both by the person with dementia and by his or her carer. There was a vivid sense of sadness and loss that surrounded dementia and it was difficult not to become immersed in these feelings. I remember discussing this group with my supervisor, and we talked about how, as Mental Health professionals, dementia is one condition that we work with which remains a potential threat to all of us. Other conditions such as Schizophrenia and Personality Disorders have an earlier peak onset age, after which the older we

get the less likely it is that we will develop these disorders. However with dementia, the reverse is true, with risk increasing with older age (Jorm & Jolley, 1998). Moreover, from a psychological perspective, there is very little that can be done to reduce the symptoms of cognitive decline. As a professional, these thoughts left me with feelings of both hopelessness and helplessness regarding the people with whom I was working. As an individual, I started to dread the prospect of myself or someone close to me developing dementia. It was partly in response to these difficult feelings that I decided to channel my attention into dementia research. I may not be able to alter the course of dementia, but through my research I can help to ensure that it is understood as well as it possibly can be.

Interest in Dementia Diagnosis

A personal experience of dementia affected me particularly. My grandfather was a very capable and intellectual person. He worked as a mechanical engineer and his accolades included being part of the design team which put the bubbles into Aero bars. However, in later life he changed a great deal. His memory declined and he became very confused. My clearest memory of this was when he drank some barbecue sauce, convinced that it was in fact a glass of red wine. In addition, his gait deteriorated, and he started to shuffle. His personality changed and he become much more irate at things, when he had been a very passive and quiet man. With hindsight, I am convinced that he had dementia, but this was never formally diagnosed.

The reasons for his lack of diagnosis are not clear and having limited evidence, I have to recognise the possibility that an underlying dementia process may not have been present. It did however make me think about reasons why some people who

have dementia may not get a diagnosis. In my grandfather's case, it is possible that he was a victim of the ascertainment bias in the assessment process (Tuokko, Garrett, McDowell, Silverberg & Kristjansson, 2003), whereby despite experiencing cognitive decline he failed to reach the absolute threshold level required for dementia diagnosis. As such it is appropriate that my research looks at how dementia is diagnosed in pre-morbidly high functioning people. However, I can't help but wonder whether my grandfather ever actually went to his GP about his memory concerns. If not, what were his reasons for this? Was he unaware that he may have had dementia, or was he in denial about his symptoms?

I also thought about the influence my Grandmother had. Carers' perceptions of dementia play a large role in the decisions of whether or not people seek help, as often it is carers who are first to notice the presence of cognitive decline. It is possible that she did not encourage him to seek help as she did not want to admit that anything was wrong. Alternatively, she may not have perceived any benefits in seeking help. Lots of people that I have talked to during my research, were unaware that medications exist to slow the progression of dementia. If people are unaware of such benefits, then they will be less likely to seek help, especially given the stigma that surrounds conditions such as dementia. Further research is needed to explore the potential barriers which prevent people from accessing memory services.

Accessing Patient Information

One of the biggest challenges of this research was accessing clients' medical files. When I first talked about my research idea with my supervisors, we were very excited at the thought of using existing information that had already been collected from memory clinics. We anticipated that it would be quicker to access this

information and consequently I would be able to collect more data, making the findings more representative of the general public. Moreover, the fact that the information was taken from existing memory services meant that it added richness to the research in the respect that this is what is actually happening in NHS memory clinics.

Having carried out small scale research projects as part of the clinical doctorate, I naively expected that I would be able to access this information without too many difficulties. Given that patients had already consented for the memory assessment to happen, I did not anticipate needing to gain consent again. Section 33 of the Data Protection Act (1998) cites research as an exception to some of the eight data protection principles, provided that set criteria are met. It states that identifiable information may be accessed for the purposes of anonymising data for research. This is provided that the research is in accordance with the original purpose that the data was collected, and that the research will not cause any substantial damage or distress to the participants involved. However, this research may only be carried out by a member of the direct clinical care team. It does not apply to researchers from outside the service. Given that I was not a member of the direct care team, approval was required to use this data.

NIGB Application

There are two ways to gain approval to access existing clinical information, either by speaking to each individual directly and getting their written consent to do so, or by approval from the National Information Governance Board for Health and Social Care (NIGB). The NIGB is an independent body that was set up in order to ‘promote, improve and monitor information governance in health and adult social

care' (NIGB, 2012). Under section 251 of the National Health Service Act (2006), the NIGB is able to recommend that the common law duty of confidentiality is set aside so as to access identifiable information without individual consent. This can occur in situations where there is insufficient anonymous data and it would not be practicable to gain individual consent.

Initially it was felt that it was not practicable to gain individual consent on a person-by-person basis for the present study. I did not have any contact with any of the dementia clinic[4] patients. To avoid breaking confidentiality, contact would have had to be initiated by a current member of care staff. In cases where patients were still open to the dementia clinic, this contact could potentially have been made by members of the Psychiatry team. He or she could have asked patients whether they would be happy to be contacted by a researcher, in order to ask permission to access his or her memory clinic file. However, in cases where the files were closed to the dementia clinic, the initial contact would have had to be made by a clinician that is known to them, such as their General Practitioner (GP). Unlike the dementia clinic, where the client is seen on a regular basis, the GP would not have been scheduled to see clients routinely, so specific contact would be needed. This would have required the GP to take on additional tasks. Given the large number of patients' datasets required for this study, this approach did not seem like a viable option. Therefore an application was submitted to the NIGB requesting that the common law duty of confidentiality be set aside.

[4] A person is assessed for dementia at the memory clinic, and then attends the dementia clinic for ongoing medication and support once they have been given a diagnosis of dementia.

The NIGB is a valuable body as it helps to safeguard the use of personal data and ensure that the eight principles of the Data Protection Act (1998) are upheld. It not only advises on the use of section 251 of the National Health Service Act (2006), but it supports improvements in national information governance practice by citing good practice guidelines, and monitors relevant information governance trends within the health and social care field. These strategies help to minimise the misuse of data and reduce breaches of confidentiality.

Unfortunately, my initial application to the NIGB was refused. The committee had concerns about the following areas:

- The level of access required to highly sensitive data
- Compliance with the third principle of the Data Protection Act (1998)
- The identification of a practicable alternative to carrying this research out without consent by undertaking it on a prospective, consented basis.

These concerns were very frustrating and for a while put me off research altogether. I felt that all my hard work in developing the research project to this point had been in vain; especially given that I felt that the findings might potentially be very exciting and that the aims of the research were in the best interests of the public. Moreover, I was told by the NIGB that with more time and resources I could gain individual consent from each and every person. This gave me a sense that only large research organisations, with better resources, would be able to carry out research projects like this. With only seven months left before my thesis submission deadline I was faced with the prospect of having to start all over again.

I was surprised by the NIGB's first concern that I would be accessing too much sensitive information. Given my role as a Trainee Clinical Psychologist I am in no doubt about my own abilities to maintain confidentiality, as I do so routinely. I appreciate that identifiable information should only be accessed as a last resort, but in the absence of an existing anonymous database, I felt that creating one was justified. All of the information that I wanted to access was within a Psychologist's remit, as it pertained only to Mental Health services. It therefore felt that tasks which I carry out regularly in my clinical practice were being scrutinised. As such I felt that the NIGB's concern was unjustified and I struggled to think of ways in which I could overcome this. Fortunately, with the help of my supervisors, we were able to come up with a solution. It was possible to check the database to see whether people had been referred to the service for reasons other than the memory clinic; if they were, it was proposed that these patients' files were excluded from the research. As such the minimum possible amount of information was accessed. On appeal, the NIGB accepted the proposed solution.

After gaining some distance, I now have a better appreciation of the NIGB's concerns. I understand that not all researchers are practiced at dealing with confidential information on a routine basis. Therefore limiting access to data helps reduce the risk of confidential information being mistreated. Moreover, access to the minimal amount of sensitive data helps to protect the welfare of the researcher. Highly sensitive mental health details may be distressing to people who are unaccustomed to them. Therefore it is in everyone's best interests, that the minimum amount of data is accessed.

The NIGB's third concern was resolved when the NIGB were informed that a prospective study was not possible due to changes in the way that dementia assessments are currently carried out in the local memory services, meaning that sufficient data for the research would not be present.

One obstacle remained though, regarding the NIGB's second concern that only the minimum amount of data necessary should be accessed. In order to give me permission to carry out the research, the NIGB required me to access only the minimum sample size needed to answer my research question. To me this remains a conundrum as it seems as if the principles of the Data Protection Act (1998) are at odds with the purposes of research. The present research study was novel and therefore it did not have an existing effect size from which to derive sample size. Effect sizes could only be calculated retrospectively, once the study was underway. To overcome this obstacle I provided the NIGB with broad and general sample size estimates (Coaley, 2010, p 61), until specific sample sizes could be determined. In future, the NIGB may need to consider being a bit more flexible with this principle in order to facilitate research. However, it is still potentially worrying that research can be carried out using a minimum sample size alone. This leaves research vulnerable to being underpowered, if any subsequent data has to be excluded on the basis of anomalies. More thought may be needed to constructively align these contradictory perspectives.

Potential Improvements to the NIGB Process

Having acknowledged the importance of the NIGB's role, there are a few things that could be done to help facilitate the undertaking of research in future. Firstly I felt frustrated by how long it took for my application to be processed. As a trainee,

carrying out this research as part of my doctorate, I had strict deadlines that I needed to meet. However, the NIBG did not appear to be sympathetic to these constraints. From the time of my initial inquiry to the final approval, the application process took six months to complete. This is a third of the allotted time that I had available to complete the whole project. This might prevent future research studies from happening if they have a limited amount of time available.

My second concern relates to the lack of communication. In the initial stages, I found it very difficult to get answers to queries that I had regarding my NIGB application. Given that this process was new to me, and I did not know anyone else who had previously applied to the NIGB, I inevitably had lots of questions. I found it difficult to understand exactly what answers were required on the application form. For example, the application requested both Corporate and System Level Security Policies, and I was unsure if these policies applied to my research, and if so, where to obtain them. Perhaps there is a need for some further online guidance or sample applications to help people who are less familiar with this type of research.

Finally the process may have been easier had I been given the opportunity to discuss the committee's concerns with them face to face. Some of their initial queries could have been resolved straight away if I had been allowed to expand on particular details from my application. As it was, my application was refused and I had to wait a further two months while it went to appeal. Consequently I came very close to not carrying out this project at all. In future, where concerns are raised perhaps the NIGB could provide additional suggestions as to how the research may be facilitated in a manner in keeping with the Data Protection Act (1998).

Future Research

There is certainly scope to carry out more research into how people are diagnosed with dementia. For my empirical study, a quantitative methodology was adopted. However, I would be interested to explore people's experiences from a qualitative perspective. The findings from my empirical paper show that people with high pre-morbid intellectual abilities suffer greater cognitive decline at the point of being assessed for dementia. However, it fails to determine why this may be. Qualitative accounts of people's journey through the process of dementia diagnosis may help to illuminate this further. This could include when and by whom, the first signs of cognitive decline were noticed, and at what point people decide to seek help from healthcare professionals as a result. It would also be important to take into account the viewpoints of people who have never accessed any dementia services, although these people may be difficult to find. Such research may help to highlight potential barriers to accessing services, which can consequently be addressed. An increased understanding of these barriers may enable people to access the support that they need.

Dementia: A National Challenge

On a positive note, the need for greater dementia research has recently been acknowledged at a national level. The Alzheimer's Society has recently released its report Dementia 2012: A National Challenge. The report describes the escalating number of people with dementia, and the subsequent costs of dementia services. As a result David Cameron has labelled dementia a 'national crisis'. Speaking at an Alzheimer's Society conference in March, 2012 he described how the levels of dementia diagnosis, understanding and awareness are 'shockingly low' and that much more research is needed to increase our understanding of the condition

(Cameron, 2012). Consequently, Cameron has pledged to double the national dementia research budget and he aims for the UK to become a world leader in dementia research. This is fantastic news for the field of dementia, as it may be finally getting the national recognition that it deserves. Hopefully this extra research will help to demystify dementia and allow for the development of better treatments to help improve the quality of the lives of those individuals that are affected by it.

Maximising Future Research

There is potential for further dementia research to be conducted using retrospective research designs. There is a wealth of existing data which is routinely collected by dementia services, which could be used to answer a variety of research hypotheses. However, thought is needed as to how to gain individual consent to use this data, in a way that is practicable. Perhaps patients could be asked from their initial contact with services, whether they consent to their clinical files being accessed for the purposes of research or not. That is not to say that this would give researchers permission to access any information that they wish, as they would still be governed by ethical procedures and the principles of the Data Protection Act (1998). Effectively, it would mean extending section 33 of the Data Protection Act (1998) to include researchers outside of the direct care team. This would allow researchers access to a greater amount of data.

Alternatively, if there was concern about accessing patient-identifiable information, then more work could be done to produce an anonymous database from the existing clinical information. As electronic medical files become more and more commonplace, it should be relatively easy to effectively anonymise patient data.

This would help to maximise the research that can be carried and increase our understanding of both dementia and current clinical practice. Again ethical procedures would help to safeguard access to this data and to ensure that information was not misused. If this was done sensitively, it would allow for data to be combined from multiple sites, so as to help collate evidence and notice national trends. This may be particularly useful with less common dementia subtypes which do not present as often to memory clinic services. By increasing the amount of research possible, this helps to ensure that clinical practice is kept up-to-date and consequently the best possible care can be given to people with dementia.

My Hopes and Fears about My Research

It is my hope that the findings from my present research study will be used to alter the way that people with high pre-morbid intellectual functioning are diagnosed with dementia. My research has highlighted the importance of using relative amounts of cognitive decline within the assessment process, rather than relying on absolute values. In future I would expect clinicians to routinely estimate a person's pre-morbid levels of intellectual functioning, in order to determine the amount of cognitive decline that they have undergone. My greatest fear would be that these findings are not recognised in any way, and that pre-morbidly high functioning people with dementia continue not to be diagnosed promptly.

Clinically, I have gained a much better understanding of the research process. It has become clear to me how important it is for clinical practice to be constantly evaluated. This requires an up-to-date understanding of both mental health disorders and therapeutic approaches, so that the best possible clinical intervention can be implemented. As scientist-practitioners, Clinical Psychologists are uniquely

positioned to be able to carry out this work. Our dual training in both research skills and therapeutic interventions means that not only can we research gaps in clinical knowledge, but we can then use those findings to improve our clinical practice in a meaningful way. This is a real strength of our profession, and one which needs to be nurtured.

In future I sincerely hope to be able to continue to work as a Clinical Psychologist who carries out research, although I know that this may be difficult to achieve. All too often clinicians have to deal with increasingly large caseloads which occupy their time, leaving little space for research. As a result this area can get overlooked, or can be left to be done by people who are solely researchers. I believe that to be the best possible clinician it is important to keep challenging the way that clinical work is carried out and not to take things for granted. This will help to ensure that services remain effective, and deliver the best possible care. I will therefore need to think carefully about how to ensure that I continue to carry out research when I become a qualified Clinical Psychologist.

Conclusions

Despite setbacks along the way I have thoroughly enjoyed the research process. At times it has been difficult to keep myself motivated, but overall I feel that I have gained a lot from carrying out this study. It is encouraging to hear that the Government has started to recognise the importance of dementia research, and I hope that the additional funding will help to increase both public and professional knowledge about dementia. Consideration is needed of how to make the most effective use of existing data, in order to maximise the lessons that can be learnt from clinical practice. However difficult it is to access existing data, it does not

mean that it should not be used, and with a little extra thought this can be achieved. This thesis is testimony to that fact.

I still feel anxious about one day being diagnosed with dementia. However, through this research I have increased people's awareness of some key aspects in the assessment and diagnosis of dementia. Hopefully through awareness of the importance of considering relative amounts of cognitive decline, a greater number of people with high pre-morbid intellectual functioning will be diagnosed as promptly as people with other levels of pre-morbid intellectual functioning.

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Appendices 1-4: Ethical Approval

Appendix 1: Coventry University

Coventry University
Priory Street
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Telephone 024 7688 7688

Professor Ian M Marshall
Pro-Vice-Chancellor (Research)

Coventry University

TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

21 March 2011

Dear Sir/Madam

Researcher's name: **Miss Emilie Oakley**
Project Title: **Diagnosis of dementia and relative cognitive decline in people with high levels of premorbid intellectual functioning**

The above named has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this applicant and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

Professor Ian Marshall
Deputy Vice-Chancellor, Academic

Enc

Pro-Vice-Chancellor's Office
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THE QUEEN'S ANNIVERSARY PRIZES FOR HIGHER AND FURTHER EDUCATION 2007

Appendix 2: Black Country Research and Ethics Committee

National Research Ethics Service
NRES Committee West Midlands - The Black Country
Prospect House
Fishing Line Road
Redditch
Worcestershire
B97 6EW

Telephone: 01527 582 533
Facsimile: 01527 582 540

20 May 2011

Ms Emilie Oakley

Dear Ms Oakley

Study title: **Diagnosis of dementia and relative cognitive decline in people with high levels of premorbid intellectual functioning**

REC reference: **11/WM/0110**

The Research Ethics Committee reviewed the above application at the meeting held on 09 May 2011. Thank you for attending to discuss the study.

Ethical opinion

Discussion with the researcher

- The Committee wanted to know if you had received a response from the National Governance Board (NGB). You said that she had not yet received a response to her request to be able to access the data and set aside the consent process.
- The Committee asked if you would usually be able to access patient's files. You said that you are authorised to access some patient's files within the clinic you are based but not for all of the other clinics you are hoping to include in the study.
- The Committee informed you that the committee would need to see the response from the NGB. You agreed to forward this once a response was received.

Decision

The Committee concluded that the study be given a **favourable opinion with conditions** as set out below.

Condition

1. The NGB must agree to the access of patient's data and the Committee must be

forwarded a copy of this agreement.

Contact for further advice: Co-ordinator.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of insurance or indemnity		01 July 2010
Investigator CV		30 January 2011
Letter from Sponsor		21 March 2011

Other: CV Tom Patters		21 March 2011
Protocol	v3	19 March 2011
REC application		25 March 2011
Referees or other scientific critique report		22 October 2010
Summary/Synopsis	v1	21 March 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/WM/0110 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp

Dr Jeff Neilson
Chair

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in England

Appendix 3: Research and Development Committee

NHS
Partnership Trust

Local Research Network

August 26th 2011

Ms Emilie Oakley
The Robertson Centre
Kidderminster General Hospital
Bewdley Road
Kidderminster
DY11 6RJ

Dear Emilie

Project Title: Diagnosis of Dementia and Relative Cognitive Decline in People with High Levels of Premorbid Intellectual Functioning
R&D Ref: PAR290311
REC Ref: 11/WM/0110

I am pleased to inform you that the R&D review of the above project is complete, and the project has been formally approved to be undertaken at Partnership Trust. Your research activity is now covered by NHS indemnity as set out in HSG (96) 48, and your trial has been entered onto the Trust's database.

The following documents were reviewed:

- **Protocol** V3 March 19th 2011
- **NHS R&D Application Form** 68717/200124/14/705
- **Site Specific Information Form** 68717/200136/6/450/85275/208838
- **NRES Approval Letter** May 20th 2011
- **NIGB Notice of Approval** August 24th 2011

Your responsibilities are set out in the attached agreement, which must be signed and returned to the R&D Office. You should keep a copy for your records.

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF) and to ICH-GCP standards. In order to ensure that research is carried out to these standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors.

The duration of Trust approval extends to the date specified in the R&D application form. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors. Research must commence within two years of the REC approval date and within six months of NHS Permission.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely

Rebecca Steele
Research & Development Facilitator

Enc: PI agreement

Cc: Dr Tom Patterson (CI)
Coventry University (Sponsor).

NIGB

Ethics and Confidentiality Committee

NHS Connecting for Health,
Floor 7,
New Kings Beam House,
22 Upper Ground,
London,
SE1 9BW.
Tel: (020) 7633 7052

Ms Emilie Oakley
Worcestershire NHS
Clinical Psychiatry
Coventry University
Priory Street
Coverntry
CV1 5FB

24 August 2011

Dear Ms Oakley

ECC 6-02(FT3)/2011 Diagnosis of dementia and relative cognitive decline

Thank you for your application for support under section 251 of the NHS Act 2006 and the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support') to process patient identifiable information without consent. This resubmission was considered at the NIGB Ethics and Confidentiality Committee meeting on 28 July 2011.

Context

This application requested section 251 support in order to access records held by five NHS memory clinics to extract anonymised data. The aim of the study was to explore whether there was a difference in the amount of cognitive decline that people with high levels of premorbid intellectual function must undergo before being diagnosed with dementia, when compared to people with other levels of premorbid intellectual function.

Application history

This application was originally processed via the fast track procedure as it was noted that no identifiable data would leave the NHS site on which it was legitimately held. Following this review an outcome was provided on the 14 June which detailed that members were unable to provide a recommendation of support due to concerns over the level of access required to highly sensitive data, compliance with the third principle of the Data Protection Act 1998 and the identification of a practicable alternative to carrying this out without consent by undertaking on a prospective, consented basis.

Outcome

Members agreed to provide a favourable recommendation under section 251. This recommendation of support was subject to the following standard and specific conditions of approval:

Specific conditions of approval

1. That where individuals were still in follow up at the memory clinic they will be approached for their consent prior to accessing their record.

2. Provision of a favourable REC opinion to the NIGB Office **(received 28/07/2011)**

3. Confirmation of satisfactory security arrangements. **(confirmation provided 19/08/11)**

As the above conditions have been accepted or met this letter confirms your final favourable recommendation for section 251 support. I will arrange for the register of applications on the NIGB website to be updated with the details of this study.

Annual Review

Please note that your approval is subject to submission of an annual review report to show how you have met the conditions or report plans, and action towards meeting them. It is also your responsibility to submit this report on the anniversary of your final approval and to report any changes such as to the purpose or design of the proposed activity, or to security and confidentiality arrangements. Please ensure that this is received approximately 8 weeks prior to this deadline.

Please do not hesitate to contact me if you have any queries arising from this letter.

Yours sincerely

Claire Edgeworth
Deputy Approvals Manager

Appendices 5-6 Research Amendments Approval

Appendix 5: Black Country Research and Ethics Committee

NRES Committee West Midlands - The Black Country
Prospect House
Fishing Line Road
Redditch
Worcestershire
B97 6EW

Tel: 01527 582537
Fax: 01527 582540

25 October 2011

Ms Emilie Oakley

Dear Ms Oakley

Study title:	**Diagnosis of dementia and relative cognitive decline in people with high levels of premorbid intellectual functioning**
REC reference:	**11/WM/0110**
Amendment number:	**AM01**
Amendment date:	**26 September 2011**

The above amendment was reviewed on 12 October 2011by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
NIGB Letter		24 August 2011
Participant Consent Form: Consent form	V1	23 September 2011
Protocol	v4	23 September 2011
Notice of Substantial Amendment (non-CTIMPs)	AM01	26 September 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/WM/0110:	**Please quote this number on all correspondence**

Yours sincerely

Mrs Jacqueline Sedgwick Assistant Coordinator on behalf of
Dr Jeff Neilson
Chair

E-mail: Jacqueline.sedgwick@westmidlands.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Tom Patterson,*
NHS
Dr Kelly Spencer,

Appendix 6: Research and Development Committee

Steele Rebecca (RKB) R&D Facilitator 29/11/11

Re: Diagnosis of Dementia and Relative Cognitive Decline in People with High Levels of Premorbid Intellectual Functioning.

REC Ref: 11/WM/0110

Dear Emilie,

Following review of substantial amendment number 01 for the above study, NHS Partnership Trust confirms they can accommodate this amendment. The amendment may therefore be immediately implemented at this site under the existing NHS Permission. Please note that you may only implement changes that were described in the amendment notice.

The following documents were reviewed:

- Notice of Substantial Amendment form September 24th 2011
- REC favourable opinion letter October 25th 2011
- **Protocol** Version 4, September 23rd 2011
- **Participant Consent Form,** Version 1, September 23rd 2011.

Thank you for keeping R&D informed.

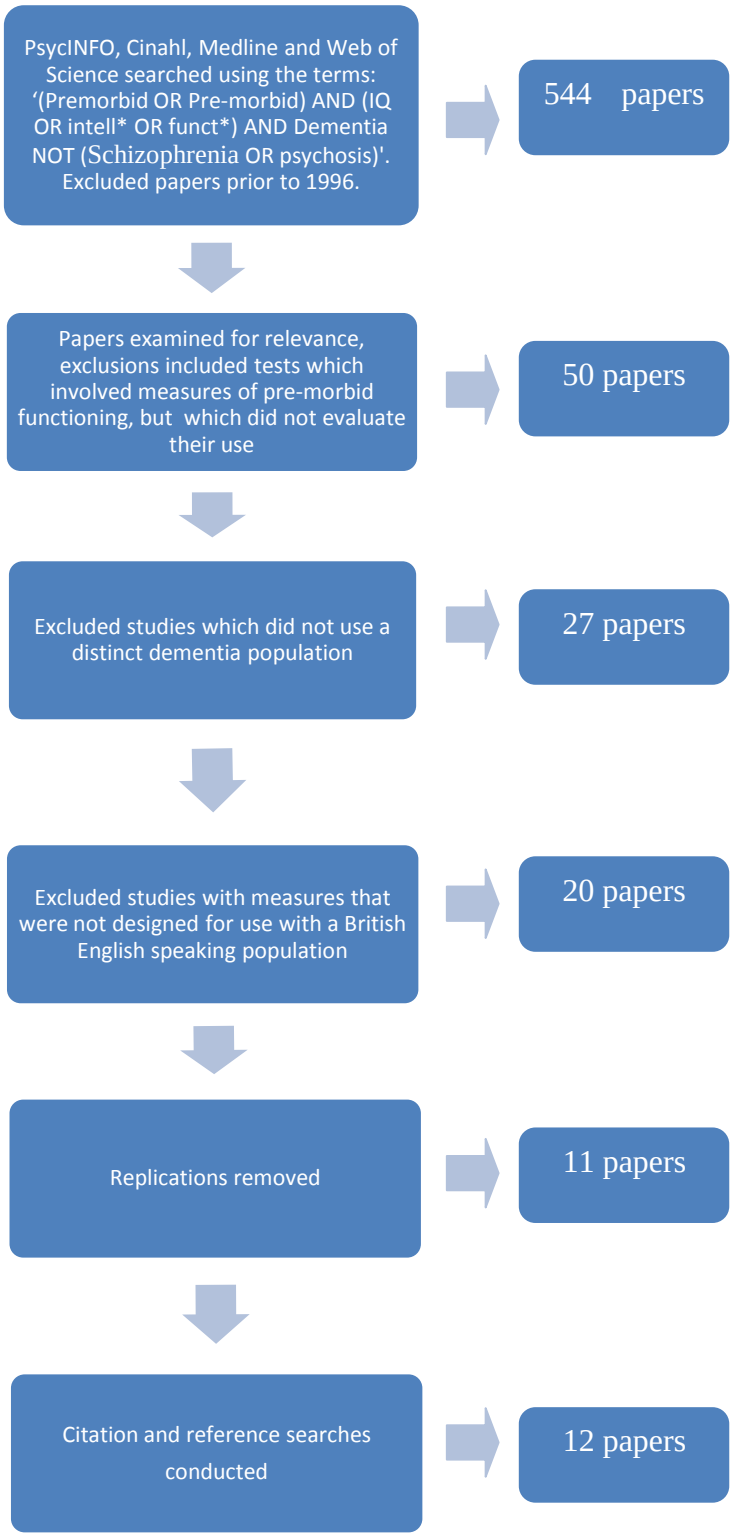
Best wishes

Rebecca Steele
CLRN R&D Facilitator

The Clinical Research Network

Supporting research to make patients, and the NHS, better

Appendix 7: Literature Search Strategy



Appendices 8-9 Measures

Appendix 8: Wechsler Test of Adult Reading (WTAR)

WTAR Word List - UK pronunciation guide

Say, **I will show you some words that I will ask you to pronounce.** Place the WTAR Word Card in front of the examinee. As you point to the card, say, **Beginning with the first word on the list, pronounce each word aloud. Start with this word** (point to item 1), **and go down this column, one after the other, without skipping any. When you finish this column, go to the next column** (point to the second column). **Pronounce each word even if you are unsure. Do you understand?** When you are sure that the examinee understands the task, say, **Ready? Begin.**

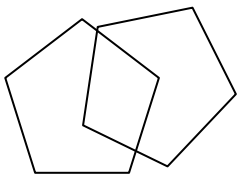
	Item	Pronunciation	Score (0, 1)		Item	Pronunciation	Score (0, 1)
1.	again	ah-GEHN ah-GAIN *or* uh-GEHN or uh-GAIN		26.	conscientious	con-shee-EN-shss	
2.	address	ah-DRESS *or* uh-DRESS		27.	homily	HOM-ih-lay *or* HOM-ih-lee	
3.	cough	kawf *or* kof		28.	malady	MAL-uh-day *or* MAL-uh-dee	
4.	preview	PREE-vyue		29.	subtle	SUH-tl	
5.	although	awl-THO		30.	fecund	FE-cund *or* FEE-cund	
6.	most	mohst		31.	palatable	PAL-ah-tuh-bul *or* PAL-uh-tuh-bul	
7.	excitement	eck-SITE-munt *or* ik-SITE-munt		32.	menagerie	meh-NA-juh-ree	
8.	know	noh *or* no		33.	obfuscate	OB-fuh-skate	
9.	plumb	plum		34.	liaison	lee-AY-zon *or* lee-AY-zn	
10	decorate	DEK-oh-rate *or* DEK-uh-rate		35.	exigency	eks-IH-jen-say *or* eks-IH-jen-see	
11.	fierce	fee-us *or* feerss		36.	xenophobia	zen-oh-FO-bee-uh	
12.	knead	need		37.	ogre	OH-gur	
13.	aisle	iyle		38.	scurrilous	SKUR-ih-lus *or* SKUR-uh-lus	
14.	vengeance	VEN-jnss		39.	ethereal	ih-THEE-ree-ul *or* ih-THEER-ee-ul	
15.	prestigious	pre-STIJ-us *or* pre-STEEJ-us		40.	paradigm	PAH-rah-dime	
16.	wreathe	reeTH		41.	perspicuity	per-spuh-KYEW-uh-tee	
17.	gnat	nat		42.	plethora	PLETH-oh-rah *or* PLETH-eh-rah	
18.	amphitheatre	AM-fih-thee-uh-ter		43.	lugubrious	loo-GOOB-ree-uss *or* loo-GOO-bree-uss	
19.	lieu	loo *or* l(y)oo		44.	treatise	TREE-tiz *or* TREET-iz	
20.	grotesque	gro-TESK		45.	dilettante	DILL-ih-tan-tay *or* DILL-uh-tahnt	
21.	iridescent	ihr-ih-DESS-unt *or* ihr-uh-DESS-unt		46.	vertiginous	ver-TIDJ-in-iss	
22.	ballet	BA-lay *or* ba-LAY *or* bal-ay		47.	ubiquitous	you-BIC-wuh-tiss *or* you-BIC-wuh-tus	
23.	equestrian	eh-KWESS-tree-un *or* ih- KWESS-tree-un		48.	hyperbole	hy-PER-bul-lay *or* hy-PUR-bul-lay	
24.	porpoise	PAW-pss *or* POR-poyz (Scots)		49.	insouciant	in-SOO-see-yunt	
25.	aesthetic	ess-THET-ik *or* ees-THET-ik		50.	hegemony	heh-GEM-o-nee *or* heh-JEM-o-nee *or* HEH-geh-mon-ee	
						WTAR Raw Score	
						WTAR Standard Score	

Appendix 9: Mini Mental State Examination (MMSE)

PATIENT'S NAME: _____

Date: _____ Client's Highest Level of Education: _____

Maximum Score	Score	
		ORIENTATION
5	( )	What is the (year) (season) (date) (day) (month)?
5	( )	where are we: (state) (county) (town) (hospital (floor)?
		REGISTRATION
3	( )	Name 3 unrelated objects (i.e.: apple, table, penny)
		Then ask the patient all 3 after you have said them.
		Give 1 point for each correct answer. Then repeat them
		until the patient learns all 3.
		Count trials and record. Trials _____
		ATTENTION AND CALCULATION
5	( )	Serial 7's. 1 point for each correct. Stop after 5
		answers. Alternatively spell "world" backwards.
		100 – 93 – 86 – 79 – 72 – 65 – 58
		RECALL
3	( )	Ask for 3 objects repeated above. Give 1 point for each.
		LANGUAGE
9	( )	Name a pencil, and watch (2 points)
	( )	Repeat the following: "No ifs, and or buts." (1 point)
	( )	Follow a 3-stage command:
		"Take this paper in your right hand, fold it in half,
		and put it on the floor." (3 points)
	( )	Read and obey the following: "Close your eyes" (1 point)
	( )	Write a sentence. (1 point)
	( )	Copy design. (1 point)
	_____	Total Score (Out of 30)



23 OR LESS: HIGH LIKELIHOOD OF DEMENTIA

25-30: NORMAL AGING OR BORDERLINE DEMENTIA

Appendix 10: Coding for Education

1= Finished school

2= Further Education

3= Higher Education

4= Masters

5= Doctorate

Appendices 11-12: Participant Information

Appendix 11: Cover Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

Dear

Please find attached a letter about some research that is being carried out locally. It is being supervised by Dr Tom Patterson, Clinical Psychologist at and Ms Jane Muers, now Honorary Research Fellow at Coventry University.

Thank you for taking the time to read the enclosed information.

Yours Sincerely,

Emilie Oakley

Trainee Clinical Psychólogist/Researcher

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

Appendix 12: Participant Information and Consent Form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

Dementia Research: Can you help?

Emilie Oakley. Clinical Psychology Department, James Starley Building, Coventry University, Priory St. Coventry. CV1 5FB Tel: 024 7 688 8328 oakleye@coventry.ac.uk

I am doing research into the diagnosis of dementia. This research depends on help from people like you.

Can you help by allowing me to look at the notes made when you went to the memory clinic? These notes are kept at the memory clinic and I will look at them there.

I want to use certain pieces of information such as the scores on memory tests that you completed when you had your appointment with the memory service.

All information that I collect will be made anonymous and kept confidential. This means that any personal details that could identify you will not be used in the research.

Although the findings of this research will not benefit you directly, it could help people similar to you in future. Your decision as to whether or not to take part in this research will not affect your treatment at the memory clinic.

I will only be able to look at your notes if you complete this form and return it to me in the stamped addressed envelope provided.

If you change your mind about your notes being included you can contact Emilie Oakley at any point before 1st February 2012.

If any of this information is unclear or you would like to ask any questions about this please do not hesitate to contact Emilie Oakley (details above).

☐ I have read and understood this information

☐ I consent to my notes in the memory service being looked at by Emilie Oakley for the purposes of her research study

Name: _____

Signature: _____ Date _____

Email address (if you would like to receive a copy of the research findings when they are completed next year): _____

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

Appendix 13: Z-score Calculation

Z-scores can be calculated as*:*

$$\text{z-score} = (\times - \mu)/\sigma$$

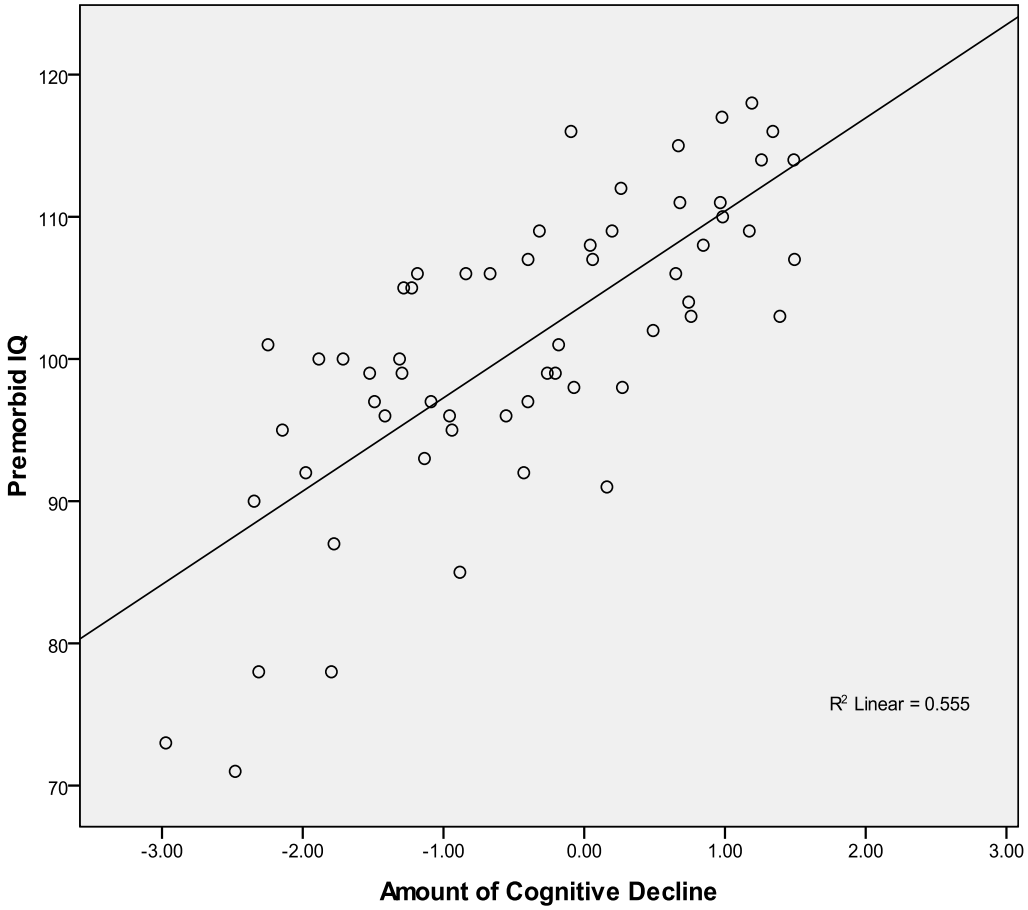
where:

$\times$ is a raw score to be standardized

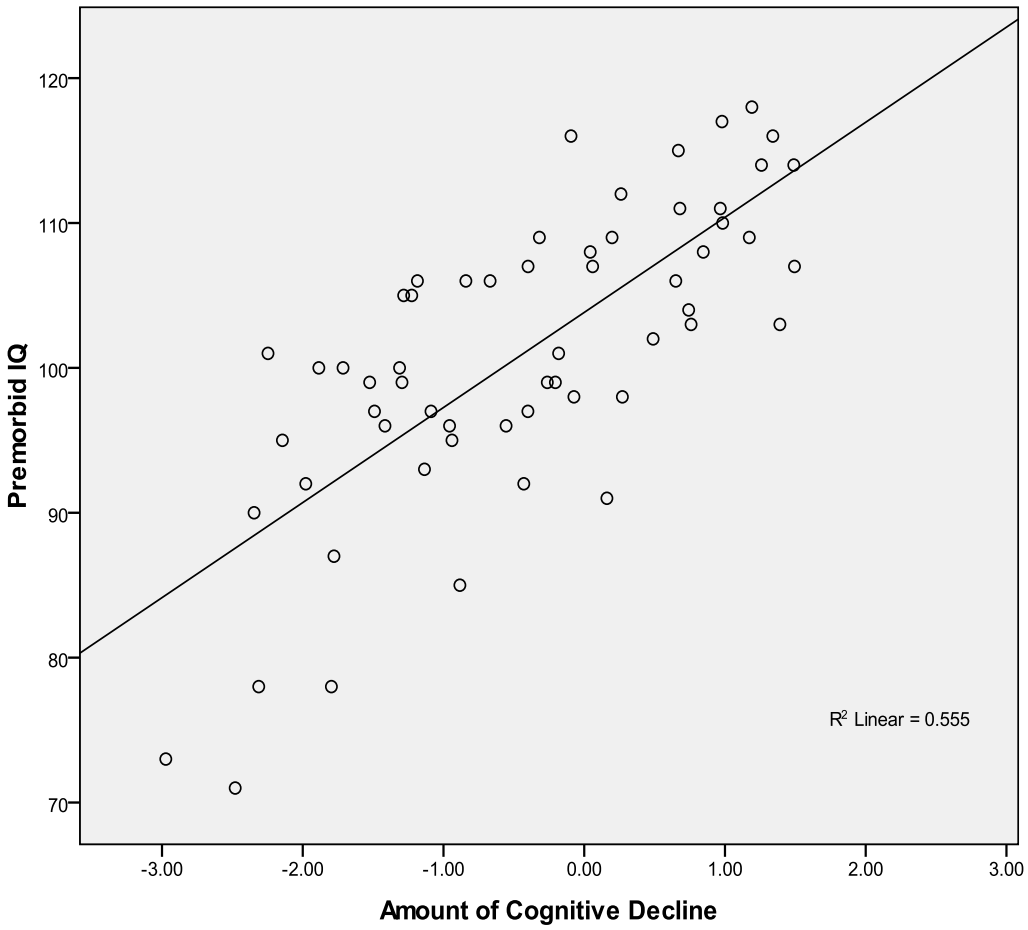
μ is the mean of the sample scores

σ is the standard deviation of the sample scores

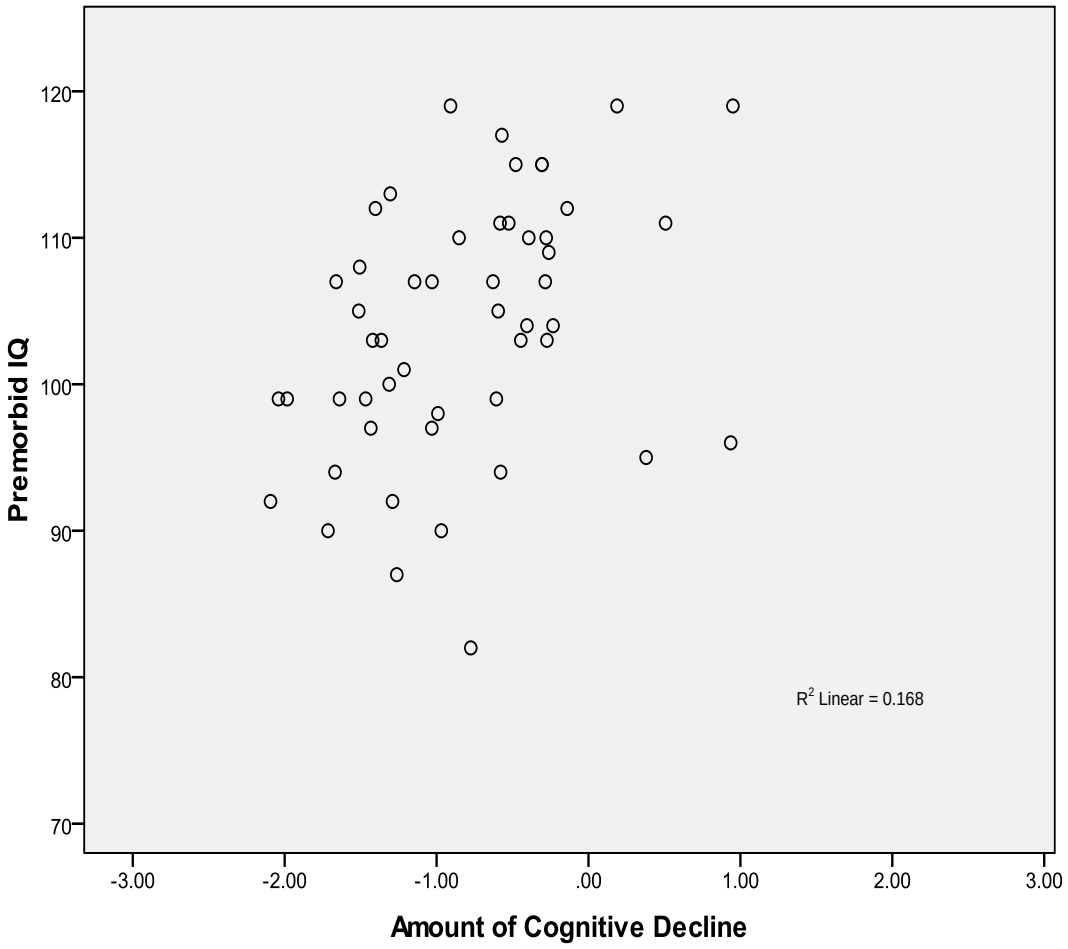
Appendix 14: Relationship between the Amount of Cognitive Decline Shown and Estimated Pre-morbid IQ in the Dementia Group



Appendix 15: Relationship between the Amount of Cognitive Decline Shown and Estimated Pre-morbid IQ in the Mild Cognitive Impairment Group



Appendix 16: Relationship between the Amount of Cognitive Decline Experienced and Estimated Pre-morbid IQ in the No Cognitive Impairment Group



Appendices 17-18: Journal Submission Guidelines

Appendix 17: British Journal of Clinical Psychology

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via *http://www.editorialmanager.com/bjcp/*. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from the website.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, and Conclusions. Review articles should use these headings: Purpose, Methods, Results, and Conclusions.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, video clips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please

note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at
http://authorservices.wiley.com/bauthor/suppmat.asp

7. Copyright

Authors will be required to assign copyright to The British Psychological Society. Copyright assignment is a condition of publication and papers will not be passed to the publisher for production unless copyright has been assigned. To assist authors an appropriate copyright assignment form will be supplied by the editorial office and is also available on the journal's website at *http://www.blackwellpublishing.com/pdf/CTA_BPS.pdf*. Government employees in both the US and the UK need to complete the Author Warranty sections, although copyright in such cases does not need to be assigned.

8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at
http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. For the full list of terms and conditions, see
http://wileyonlinelibrary.com/onlineopen#OnlineOpen_Terms

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form available from our website at: *https://onlinelibrary.wiley.com/onlineOpenOrder*

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

11. Author Services

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12. The Later Stages

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