CAN MEASURES OF DISSOCIATION, DEPRESSION, ANXIETY AND A MEASURE OF EFFORT AND ENGAGEMENT INCREASE THE PREDICTIVE VALIDITY OF DIAGNOSIS BETWEEN FUNCTIONAL MEMORY DISORDERS, DEMENTIA AND MILD COGNITIVE IMPAIRMENT

By

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A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REGULATIONS FOR THE DEGREE OF DOCTOR OF CLINICAL PSYCHOLOGY

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February 2022

OVERVIEW

This thesis is submitted as partial fulfilment for the degree of Doctorate in Psychology (Clin.Psy.D) at the University of Birmingham.
The thesis consists of two chapters.

Chapter one

Chapter one is a literature review completed using a meta-analysis to examine the internal reliability of the Dissociation Experiences Scale.

Chapter two

Chapter two presents an empirical study which explored the predictive validity of psychometric tests, and a measure of effort and engagement in addition to cognitive, personal and neurological factors as part of a standard memory assessment.

ACKNOWLEDGEMENTS

Thank you to the University of Birmingham.

Thank you to Dr Christopher Jones for his support with both the meta-analysis and empirical paper. His knowledge, expertise, time and calmness were immeasurably valuable.

Thank you to Dr Michael Ridley-Dash for allowing me to carry forward his ideas for an empirical paper. His passion for what he does has been infectious and his continued support throughout the entire Doctoral process has been instrumental.

Thank you to my appraisal tutor, Dr Michelle Fisher, for her continued care and support throughout my journey as a Clinical Psychologist trainee. My personalised programme has allowed me to achieve more than I thought was possible.

Thank you to all the clients of the memory service who agreed to participate in the empirical paper.

A special thank you to my family. Especially, my husband Kieran, my toddler Rosa-Rae and my baby on the way. Thank you for all of your love, unwavering positivity, cuddles and kisses. Thank you for wiping my tears and celebrating all of the little achievements along the way. You have given me the strength to carry through. Most of all, thank you for always giving me a reason to ensure that my life outside of being a trainee is one that is treasured.

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LITERATURE REVIEW: THE RELIABILITY OF THE DISSOCIATIVE EXPERIENCES SCALE. A META-ANALYSIS

ABSTRACT

Background

The DES and its updated version, the DES-II, are the most commonly used measure of dissociation in practice and research. The DES is a self-report measure consisting of 28 items aiming to measure the frequency of dissociative experiences in a person's daily life. The last meta-analysis to explore the internal reliability of the DES was conducted in 1996, standing over 20 years old. Since this time, to the knowledge of the author, no meta-analysis investigating the internal consistency or test-retest reliability of the DES, or of its updated version (DES-II), has been conducted with an aim of synthesising and presenting the internal consistency or test/retest reliability. Therefore, the current review investigated methodological variation, weakness and strengths in addition to exploration of factors that may moderate the internal consistency or test-retest reliability of the measure.

Method

A systematic search of the literature was completed using PsychINFO, PsychARTICLES, EMBASE, OVID, Medline and Web of Science databases. The systematic search generated 2674 articles, resulting in the inclusion of 144 papers. A meta-analysis was completed on 169 datasets from 144 primary studies to explore alpha coefficient. A meta-analysis was also conducted to explore test/retest reliability. This included a total of 12 primary studies involving 1534 participants

Results

The results of this review demonstrated a "good" weighted alpha value of 0.93 (95% CI – 0.9236-0.9331) which is far above the commonly acceptable minimum value of 0.7. The review also found a weighted average test/retest of 0.86 ($p < 0.001$) and a 95% confidence interval of between 0.83 to 0.90. A test-retest reliability coefficient of this magnitude would be considered acceptable and it is markedly greater than the generally accepted minimum internal reliability value of 0.7.

Conclusions

The alpha coefficient of 0.93 has remained consistent between Van Ijzendoorn and Schuengel's (1996) meta-analysis and the current meta-analysis despite the addition of 128 studies from across the globe. The newly added studies included different language variants and the more recently updated DES-II. It is suggested, therefore, that the alpha coefficient of the DES is accurate and stable.

INTRODUCTION

What is dissociation?

Dissociation is a concept that is central to clinical and forensic psychology. It can be described as deviation from the functions that normally provide an integration of the self, including perception, cognition, consciousness, memory, identity and affectivity (Bernstein & Putnam, 1986; American Psychiatric Association, 2013). Dissociation can happen occasionally as a part of normal functioning but can also be related to a wide range of psychiatric disorders where it is more frequent and distressing (Sar et al, 2007; O'Neil & Dell, 2009). Thus, dissociation presents on a spectrum of fleeting to persistent and abrupt to progressive (Sar, 2011). The prevalence of dissociation amongst the general population is difficult to ascertain due to its presence as part of normal life and as a feature of different clinical presentations in relation to trauma. Dissociative disorders are thought to have a lifetime prevalence of around 10% (Sar, 2011). The prevalence of pathological dissociation in European studies reports rates of 0.3% in general population (Spitzer et al, 2006), between 1.8 and 2.9% in student populations (Modestin & Erni, 2004; Spitzer et al, 2006) and between 5.4 and 12.7% (Waller et al, 2001; Spitzer et al, 2006) in randomly selected psychiatric inpatients.

Dissociation is the defining feature of the following mental health disorders: dissociative amnesia, dissociative identity, depersonalisation disorders, PTSD and borderline personality disorder (American Psychiatric Association, 2013). Dissociative psychopathology is also found in a large range of mental health problems such as obsessive-compulsive disorder (Grabe et al, 1999), schizophrenia (Spitzer, Haug & Freyberger, 1997), certain personality traits (Grabe, Spitzer & Freyberger, 1999) and affective disorder (Putnam & Carlson, 1996). Dissociation is linked to maladaptive behaviours such as self-harm (Černis, Chan & Cooper, 2019), suicidal behaviour (Foote et al, 2008) and violence (Ruiz et al, 2008; Zavattini et al, 2017) and is thought to have an important relationship with how likely someone responds to treatment (Michelson et al, 1998; Rufer et al, 2006). There is growing evidence that dissociation is a consequence of trauma (Gershuny & Thayer, 1999; Carrion & Steiner, 2000; Carlson, Dalenberg & McDadeMontez, 2012), with epidemiological studies supporting the relationship between childhood experiences of trauma and dissociative disorders (Sar, 2011).

Consequently, dissociation is a concept that is central to psychology, and its relationship with adversity in childhood highlights a neglected public health problem.

How is it conceptualised?

One of the most popular measures of dissociation is The Dissociative Experience Scale (DES; Bernstein & Putnam, 1986) and its revised version (DES-II; Carlson & Putnam, 1993). The use of the measure in psychological research is pervasive; a study by Abu-Rus and colleagues (2020) suggested that over 2200 studies in PsychInfo are listed as using the scale. Lyssenko and colleagues (2018) suggest that the wide use of DES and its variants within psychopathology assessment reflects the complexity and ubiquity of dissociation in psychopathology. Studies designed to explore the underlying structure of the DES and DES-II have been unable to provide consistent support for a specific conceptual model. Historically, conceptual models of dissociation in studies using the DES-II suggested the following domains: depersonalisation, amnesia experiences and absorption (Carlson & Putnam, 1993). This three-factor model was also found in other confirmatory factor analysis studies (Ross, Joshi & Currie, 1991; Bombi et al, 1996; Zingrone & Alvarado, 2001; Stockdale et al, 2002; Ruiz et al, 2008; Soffer-Dudek et al, 2015). However, in a study utilising principle component analysis, Ray and colleagues (1992) found that seven factors underlie the DES-II. The popularity of the DES-II is of particular relevance as there is a lack of a widely accepted conceptualisation and definition of dissociation. Despite this, it is important that dissociation can be measured reliably.

Description of the DES

The DES is a self-report measure consisting of 28 items aiming to measure the frequency of dissociative experiences in a person's daily life. The items were developed through interviews with people who have experiences of dissociative disorders and with experts in the field of dissociative disorders (Carlson & Putnam, 1993). The measure uses a response scale rather than a dichotomous format so that scores reflect a range of symptomology to quantify experiences. Persons are asked to consider what percentage of the time they experience dissociative features and are asked to mark on a 100mm line which starts at 0% (never) and ends at 100% (always). Results are recorded to the nearest 5mm and total score is the average across the 28 items, between 0 and 100. Scores of over 30 are indicative of high levels of

dissociation (Carlson & Putnam, 1993). However, higher scores do not parallel a more severe dissociative disorder as the scale measures both psychopathological dissociation and normal dissociation (Carlson & Putnam, 1993). The scale was designed to quantify dissociative experiences and to be used as a screening tool to "help identify dissociative psychopathology" (Bernstein & Putnam, p16, 1986). The DES was not intended to be used as a diagnostic instrument, although information is provided for the cut-off scores within different clinical populations (Carlson & Putnam, 1993). The DES was originally designed and intended for use within clinical populations. The scale is now frequently used in non-clinical populations. The authors argued that non-clinical populations will score within a narrow range and that the differences between scores in this range may not be meaningful (Carlson & Putnam, 1993).

Carlson and Putnam (1993) offered an alternative response set in the DES-II to reflect the difficulties practitioners found with the time-consuming nature of measuring responses to the nearest five mm in the DES. The response set on the DES-II has eleven options starting from 0% and rising by 10% to 100%. Respondents are instructed to circle one of the 11 responses. A study by Elliason and colleagues (1994, as cited in Ross, 1997) looked at the differences in response between the DES and DES-II using convergent validity and found that participants responded similarly for each. Perhaps due to their similarities, it was often found when looking at the research literature closely, authors utilise the DES-II (fixed format) but name the measure as "DES".

The DES and DES-II has been translated for use across the globe. Languages include Spanish, Hebrew, Italian, Dutch, Japanese, Turkish, Russian, Portuguese, German, Czech and French (Abu-Rus et al, 2020). Additionally, the DES which was designed for use with adults, has been adapted for use with adolescents (A-DES) and shows strong validity and reliability cross-culturally (Soukup et al, 2010). The DES has also been developed into many variants including Dissociative Experiences Scale-Revised, Dissociative Experiences Scale-Taxon and the Dissociative Experiences Scale-Comparison which are also used widely (Lyssenko et al, 2018).

Reliability of DES and variations in score

Ross (1997) argues that the DES is not only the most widely used self-report measure of dissociation, but it is also the most methodologically scrutinised. The authors of the DES, Bernstein and Putnam (1986) found that the measure has good test-retest reliability, 0.84, for 26 typical functioning patients across four to six weeks. They also found good split half reliability and significant correlations that indicated good internal consistency and construct validity. A meta-analysis by van Ijzendoorn & Schuengel (1996) found that the alpha reliability of 16 studies was 0.93 and concluded that the scale was highly consistent. The meta-analysis also concluded that the measure showed good convergent validity with questionnaires and interviews that measure dissociation. Predictive validity was measured and was found to be strong, especially concerning dissociative disorders. However, discriminant validity was found to be less established. Many validation and reliability studies since this time have suggested that the DES and the DES-II have high validity and reliability in both clinical and non-clinical populations (Frischholz et al, 1990; Carlson & Putnam, 1993; Carlson et al, 1993; Dubester & Braun, 1995; Holtgraves & Stockdale, 1997; Zingrone & Alvarado, 2001).

Study aims and rationale

Assessing the reliability of a scale involves considering whether the scale measures in a consistent and accurate way. Internal consistency is a measure of reliability which refers to the extent to which all items of a scale contribute positively to measuring the same underlying construct (Kline, 2000). Cronbach's alpha is the most commonly used measure of internal consistency (Field, 2009). Cronbach's alpha generally ranges between zero (indicating no reliable variance) and 1.0 (indicating perfect reliability). The closer the value is to 1, the more likely the measure has reliable variance with no measurement error. 0.7 is typically the acceptable cut-off score for Cronbach's alpha (Hair et al, 2010), however, Kline (2000) argues that the literature is contradictory with different classifications and ranges for what is "acceptable" and "non-acceptable". Factors such as the number of items in a scale and the number of participants completing the measure can influence the alpha value (Ponterotto & Ruckdeschel, 2007). Research by Cortina (1993) suggests that scales with over 20 items, such as the DES, can produce Cronbach's alpha above 0.7 even when item intercorrelations are small. Hair and colleagues (2010) therefore advise that more rigorous

requirements should be made of scales which have a large number of items. Increasing the number of items on a scale will result in an increase of alpha value even when the intercorrelations are the same.

Test-retest reliability in comparison, refers to a test's ability to produce similar results over time. It measures the stability of scores (the degree to which they remain unchanged) when measuring a stable construct on two or more different occasions. Measurement error is estimated by intra-individual response variability (Hays, Anderson & Revicki, 1993). Similarly to Cronbach's alpha, test-retest reliability typically ranged from 0 to 1 with values closer to 1 showing "perfect reliability" and values closer to 0 showing no reliability. Cicchetti (1994) defined test-retest reliability scores between 0.4 and 0.59 as fair, 0.60 to 0.74 as good and above 0.75 as excellent. Portney & Watkins (2015) created more conservative standards which correspond more closely with definitions of internal consistency of psychometric measurements. Their standards define values between 0.5 and 0.75 as poor to moderate, 0.75 to 0.9 as good and above 0.9 as acceptable.

It is surprising, considering the wide use of the DES and its variants that very few meta-analyses have been conducted, and only one has focused on reliability. Van Ijzendoorn and Schuengel (1996) is arguably one of the only comprehensive meta-analyses conducted in the field and it now stands at over 20 years old. Since this time, to the knowledge of the author, no meta-analysis investigating the internal consistency or test-retest reliability of the DES, or of its updated version (DES-II), has been conducted with an aim of synthesising and presenting the internal consistency or test/retest reliability. In 20 years, not only has there been a revision of the scale, but the number of times the scale has been used has advanced significantly. An updated meta-analysis will allow for investigation of methodological variation, weakness and strengths in addition to exploration of factors that may moderate the internal consistency or test-retest reliability of the measure. For example, the version of the scale, and the population of participants. A measure of dissociation that demonstrated "good" internal consistency and test-retest reliability across normal and clinical populations is vital for identification of dissociative experiences and the identified need for further investigation of dissociation.

METHOD

Identifying primary studies

Search of Electronic Databases

On 20th September 2020, a systematic search of the literature was conducted using PsychINFO, PsychARTICLES, EMBASE, OVID, Medline and Web of Science databases. The search terms that were used to identify relevant studies are shown in Table 1 below. The search terms within each construct were combined with "or" and subsequent results from each construct were combined together with "and". English language was applied as a limit to the search results.

Table 1: Search Strategy

Construct	Free Text Search Terms
Dissociative Experiences Scale	"Dissociat* Experience* Scale" DES
Reliability	"Internal consistency" Valid* Reliab* Alpha or Cronbach* "Test retest"

Inclusion Criteria

For each paper meeting the inclusion criteria, reference lists were examined for any additional appropriate studies. Inclusion criteria were kept broad, with only restrictions applying to the reporting of total alpha value and/or test-retest value. This decision was made based on the research field being diverse in terms of methodologies, diagnosis/disorder, setting, country of origin, purpose of study and timeframe. Full inclusion/exclusion criteria

are detailed in Table 2.

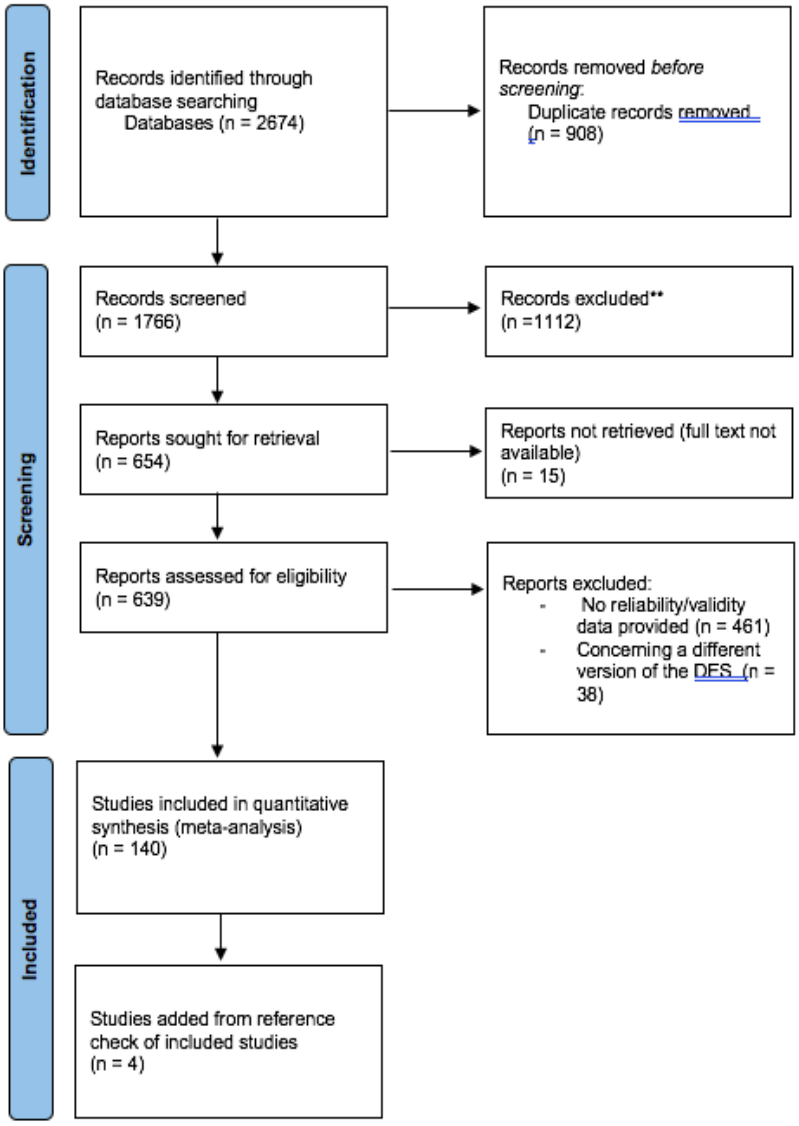
Table 2: Inclusion and exclusion criteria

Inclusion Criteria	Justification
Scale focus	
The study used the DES or DES-II and reported the "total" reliability of the scale. Studies where the reliability was not the main focus are also included providing that the reliability of the DES in included	This is to ensure that only the DES and DES-II are included as they are the most commonly used, and often mistitled for one another. The focus of the primary studies did not matter as long as the alpha value and/or test/retest value was reported (as this is the focus of the review)
The scale can be delivered in any modality	
The scale must have been completed by the participant in one sitting	The scale was designed to be completed in one sitting and variations in this method would influence the reliability of the measure which may impact on the outcome of the review
Participant focus and characteristics	
Participants must not be children (under the age of 18), and the majority of participants (over 80%) must be adults. There are no restrictions on participant language, gender, education or demographics	The review aims to explore the reliability of the DES across all possible population groups where the scale has been employed. The scale is designed for adults and therefore child populations are excluded as they may impact on the reliability of the measure and the outcomes of this review

Outcome data and study design	
No restriction on design of the study or study size, providing results are not taken from previous published worked, manufactured or reproduced	Original data from studies will be used to ensure that the calculation of overall reliability is not influenced heavily by individual study data that has been overlapped
The studies are required to report the alpha coefficient value for the total DES score and/or the test/retest value	The reporting of the reliability of the Total DES score is the main focus of the review in addition to test/retest reliability
Type of article	
The following types of articles were excluded: meta-analysis, theoretical papers, reviews, commentaries, clinical guidance, qualitative paper	These types of articles do not include the reliability data needed for this review

The systematic search generated 2674 articles, and 1766 after removal of duplicates. The study titles and abstracts were screened using the inclusion/exclusion criteria, resulting in 1112 being excluded from analysis. Papers were excluded if they were not in an English language or if they were irrelevant to subject matter of dissociation. The remaining 654 articles were sought for retrieval; however, 15 articles were unavailable for full text retrieval, resulting in 639 papers. These papers were read and reviewed for eligibility, resulting in the exclusion of 499 papers. The remaining 140 papers were included in the meta-analysis and a reference list search of these papers revealed an additional four papers which met eligibility criteria. The final number of papers included in the meta-synthesis was 144. Of these 144, some papers included an alpha value, some a test-retest value and some papers included both. The PRISMA chart (Figure 1) presents the results of the systematic search.

Figure 1: PRISMA chart - results of the systematic search and application of inclusion criteria.



A B

Quality assessment and Data extraction

The author of this report extracted the data from the papers identified in the search. A 10% random sample was checked and cross-validated by a second rater for the purposes of ensuring the quality rating and data extraction of included studies was reliable. The second rater did not differ in data extraction but did differ in their ratings on one of the quality criteria which prompted a revision in the description of ratings. Selection bias criteria was revised to include percentages in order to make the decision more quantifiable. Post revision,

5 studies were randomly selected to test the reliability of the criteria and there were no disagreements.

Risk of bias assessment

The Cochrane Collaboration Risk of Bias Tool (Higgins et al, 2011) and the Risk of Bias Assessment Tool for Nonrandomised Studies (Kim et al, 2013) were adapted to develop the quality criteria used to assess risk of bias. Higgins and colleagues (2011) suggest operationalising quality criteria which are specific and suitable for the specific types of bias expected for the literature of focus. The risk of bias was assessed through six domains: Selection Bias; Treatment Fidelity; Detection Bias; Statistical Bias; Reporting Bias; Generalisability (see Table 3). In each domain, the studies were rated as either Low, Unclear or High risk (see Appendix 1).

Table 3: Risk of bias quality framework

Domain	Details	Risk of Bias
Selection Bias	Selection bias occurs when there is a systematic difference between the characteristics of those selected to participate in the study in comparison to those who do not participate. The participants should be representative of that for which the DES was designed (adults) Have the selection method and characteristics of participants been described adequately?	High Risk - No method of how participants were selected, less than 30% of the characteristics of participants described. If any of the population are under the age of 18. If there is a predominately male or female population (>75%). Unclear Risk - The characteristics of the study population are not clearly or fully reported. This includes age range, education, socioeconomic status, ethnicity, and where and how participants were recruited. Unclear risk of bias will be chosen if the sample is predominantly male or female (>65%, <75%) Low Risk - The characteristics of the study population are clearly described and are

Domain	Details	Risk of Bias
		representative of the population for which the scale was developed. Participants should be over 18 years old, symmetrical in sex (not more than 65% predominately male or female), from a general sample or a clinically relevant sample (a known group to suffer with dissociation)
Treatment Fidelity	Was the delivery of the DES sufficiently described so that it could be replicated? Was the DES administered as per the test's author's guidelines? Were procedures in place to assess the fidelity of the administration?	High risk - No description of how DES was administered or administration in a way that is contradictory to guidelines from author (e.g., delivered as an interview or online). No mention of processes used to ensure fidelity. Unclear risk - Unclear if the protocol was followed. Where the procedure was not reported and it is unclear what setting the test was administered (e.g., 1 to 1, at home, in a group) Low risk - Test delivery and completion is clearly described with adequate adherence to the test author's recommendations. The test should be delivered on paper format in a self-report capacity.
Performance Bias	Was there any systematic difference between	High risk - Participants were rewarded for their participation in the study. Participants

Domain	Details	Risk of Bias
	participants motivation to complete the study	were informed of proposed hypotheses. It was not reported how participants were recruited. Unclear risk - It is unclear if participants were rewarded for their participation. It is unclear how much information was provided to participants prior to taking part in the study. Low risk - Participants were not rewarded for their participation. Information about the study procedures were provided in a way that does not influence the level of motivation for participants
Detection Bias	Takes into consideration any alterations made to the original measure and the use of the scale. Was the DES administered in its original or agreed format? Was the scoring completed as per the author's recommendations?	High risk - Major alterations to the test, including wording and/or scoring. Combined with or amalgamated with a different test. Only selected items of the scale were administered; the scale's developer had not approved the version; or the administration protocol was not adhered to. Unclear risk - It is unclear whether the full scale was administered, or it is unclear whether it is an approved version; or it is unclear whether the administration protocol was followed. Unclear if it has been

Domain	Details	Risk of Bias
		translated or it has been translated and alterations have been made to the questions Low risk - The full version of the scale is used (28 items), either the original version or a version approved by the scale's developer (e.g. DES, DES-II, validated language variant)
Statistical Bias	The reporting of statistical information, relating to the reliability coefficient. Considers the information reported in terms of its completeness and accuracy.	High risk - No information is provided as to how the reliability coefficient and/or test/retest reliability has been calculated. Only an estimated alpha coefficient has been reported. Unclear risk - Non-exact reliability coefficient is reported; or some data is missing (i.e. unclear whether the full sample was used to provide this value or just a subset of the sample). Low risk - Exact reliability coefficient and/or test/rest reliability is reported, and it is clear how this was calculated (i.e. no missing data).
Generalisation	Capturing the size of the sample and the ability to transfer findings to the wider population. Can the results be applied to other populations, groups or	High risk - The sample contains fewer than 40 participants. The sample size is not adequate to detect an effect. Unclear risk - The sample contains between 40 and 80 participants

Domain	Details	Risk of Bias
	settings based on the sample used?	Low risk - The sample contains more than 80 participants

Each category of risk of bias was rated as either Low, Unclear or High risk for each of the 144 studies (see Appendix 1). In instances where a single study has reported separate alpha coefficients for more than one participant group, they are reviewed as separate studies and are labelled with numbers. This increased the number of studies from 144 to 169. A low risk of bias was awarded two points, an unclear risk of bias one point and a high risk of bias was given zero points. The quality index is calculated as the sum of each of the six areas of risk of bias and therefore the maximum score a paper could achieve is 12 points. In addition to this, papers were rated based on whether or not they were designed as a psychometric validation paper. Validation papers with 100 participants or more were awarded 10 points. Papers that calculated and reported the alpha coefficient indirectly and psychometric validation papers with fewer than 100 participants were awarded zero points. The maximum score a study could receive was 22 points. The quality index is expressed as a percentage of the maximum possible score.

Selection Bias

Overall, selection bias represented the largest cause of risk, with 100 studies rated as demonstrating a high risk of bias. To be considered a low risk of bias, participants should be over 18 years old (as the measure is designed for adults) and the sample should be symmetrical in sex (not more than 65% predominately male or female). Only 25 of the studies had a mixed sex sample, with the remaining studies either not stating the proportion of males and females (studies=44) or having a predominantly male or female sample. The vast majority of studies had predominantly female samples, with 50 studies having a proportion of females which was 75% or higher. Three studies included samples with an age range that started below 18. Additionally, only a handful of studies included full sample details which included ethnicity and number of years in education. These reasons were deemed to be variables that could have influence on the reliability of the scale and thus prompted an unclear or high-risk rating.

Performance Bias

The majority of studies demonstrated an unclear risk of bias in this quality criteria (studies=94). This rating was given to any paper that did not make clear whether or not participation was voluntary without reward. 44 studies stated that they rewarded their participants with course credit or financial compensation. Rewarding participation is deemed a potential influence on the reliability of the scale and these papers demonstrated a high risk of bias.

Treatment fidelity

Overall, it was found that the majority of studies demonstrated an unclear risk (studies=72) of bias in this quality criteria. The papers given an unclear risk of bias (studies=90) did not adequately describe the administration procedure, most commonly not stating where the DES was administered. A handful of studies demonstrated a high risk of bias rating, several due to being administered online (studies= 5), verbally (studies=1) or with participants who are under the influence of alcohol (studies=1).

Detection bias

The majority of the studies demonstrated a low risk of bias in this quality criteria (studies= 95). However, a large proportion of studies showed an unclear (studies=44) and high risk of bias (studies=30). An unclear risk of bias was most commonly due to the study stating that they were using the DES but actually administered the DES-II according to the scoring details. A high-risk rating was provided mainly due to studies translating the DES back and forth using a paid translator (studies = 3), being unclear on what language the DES was administered in (studies= 21) or changing the format of the DES (studies=6).

Statistical Bias

Overall, the majority of studies demonstrated a low risk of bias. Only a few studies demonstrated an unclear risk of bias (studies=12) and no studies demonstrated a high risk of

bias. An unclear risk of bias was awarded to studies not stating clearly whether all of the participant data was used to calculate the alpha score.

Generalisation

The majority of studies demonstrated a low risk of bias in generalisability with sample sizes over 80 participants. 42 studies showed unclear risk with sample sizes between 60 and 80. 15 studies had a high risk of bias in generalisability due to sample sizes being less than 40 participants. The sample sizes and their corresponding level of risk were based on the norms of sample sizes for studies in this research field.

Summary

Overall, the level of bias demonstrated by the primary studies was quite mixed. Primarily studies had low and unclear risk of bias. Notably, the level of risk in selection bias was high with a large number of studies utilising sample populations that were predominantly female. The inclusion of only a small number of studies with high bias in any category of bias has the ability to impact on the synthesis of the meta-analysis. However, the current analysis synthesises a large number of studies and therefore will be less prone to these effects. Consequently, no action was needed.

RESULTS

Of the 144 studies reporting 169 reliability values, 141 studies reported a value for alpha and 12 studies reported a test-retest value.

Alpha Coefficient

Overview

This review aimed to explore and report upon the reliability of the DES.

There was a total of 144 primary studies, reporting 169 reliability coefficients, and representing a total of 47,791 participants. Within several of these primary studies, separate population groups had been measured (mainly a clinical sample and a general sample), resulting in multiple reporting of outcomes within a single primary study. Alpha described in these primary studies are reported in Figure 4. Participants were selected from a variety of settings including veterans, general community, University students, forensic settings, and mental health settings. Participants varied in age, but in every study were mainly adult participants over the age of 18. Country of origin and first language also varied throughout the studies.

Selection of the meta-analytic model

The distribution of primary study effects is shown in Figure 3. In the random effects model the variance of the true effect (tau^2) was calculated using the DerSimonian and Laird estimator. The fixed effects model shows clear deviation from distributional assumptions whereas the random effects model, although showing some deviation, appears to be a more appropriate fit of these data. Tau^2 was also calculated using the Restricted maximum-likelihood (REML) estimator, as this estimator has known to be robust to deviations from normality (Banks, Mao & Walters, 1985). As can be seen in Figure 2 and 3 below, the REML estimator is a better fit to the data than was the model using the DerSimonian and Laird estimator. Although some non-normality remains, most of the primary studies fall within the 95% confidence intervals for the expected normal values and suggests that the use of the REML estimate is an appropriate method for the calculation of the variance of the true effect. In addition the REML is less dependent upon assumptions of normality given its use of maximum likelihood rather than ordinary least squares in the estimation algorithm (REF).

Figure 2: QQ plot of the distribution of ARAW Alpha within the primary studies using the random effects model and the fixed effects model

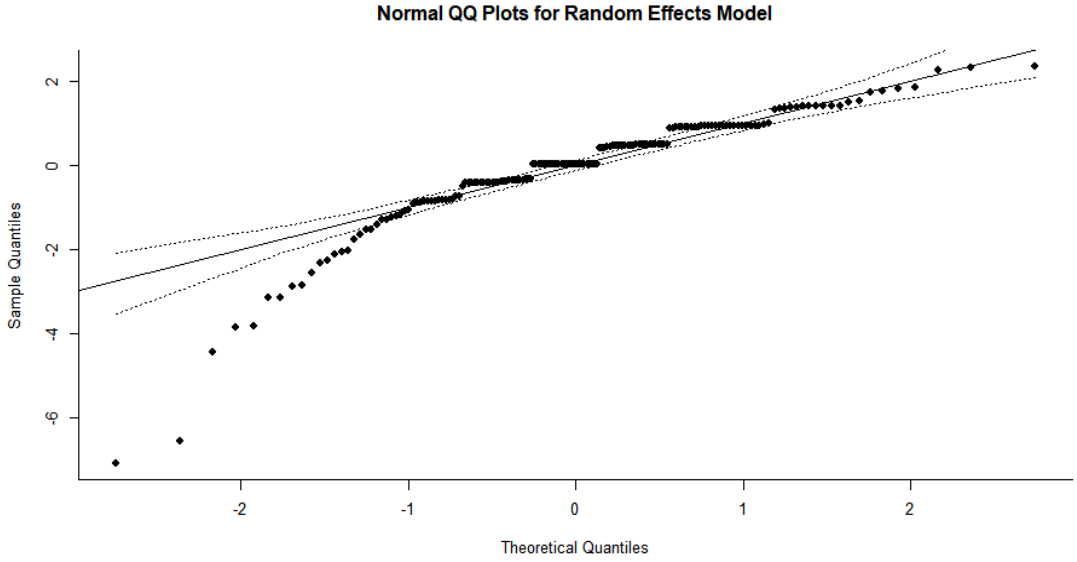
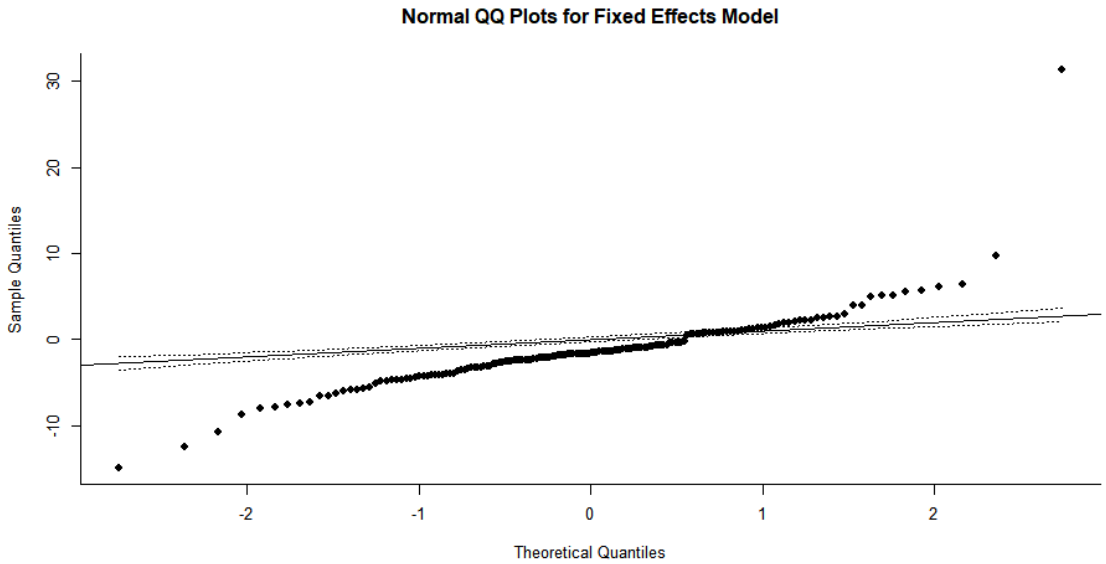


Figure 3: QQ plot of the distribution of ARAW Alpha within the primary studies using the REML model



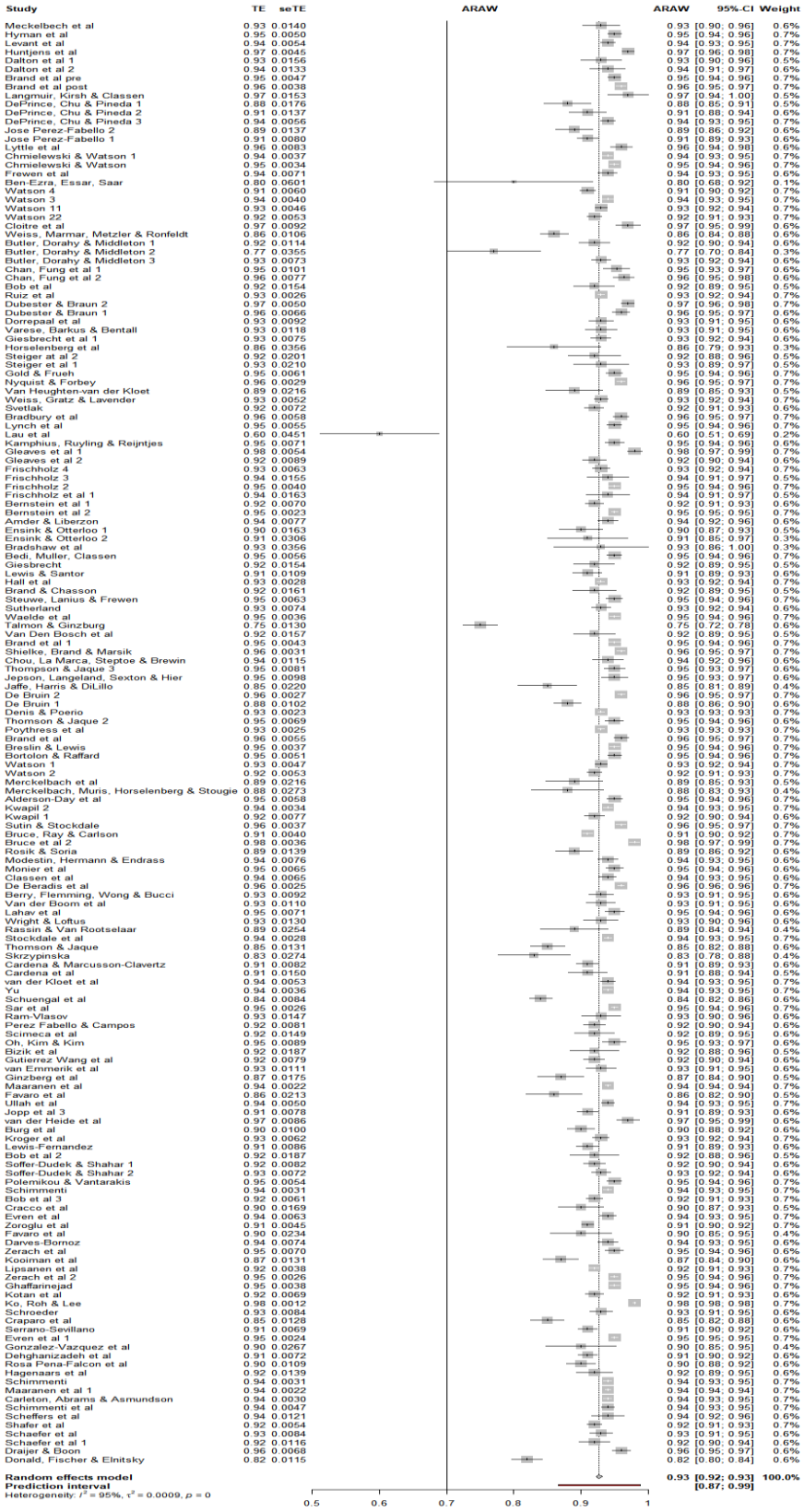
Synthesis of primary studies

A random effects model was calculated using the generic inverse variance method. The random effects model suggested a weighted average Alpha of 0.9275 ($z=365.44$, $p<0.001$) and a 95% confidence interval of between 0.9225 and 0.9324. An effect of this magnitude would be considered acceptable and is markedly greater than the generally accepted minimum internal reliability value of 0.70.

Level of heterogeneity

The lowest reported alpha coefficient was 0.6 (Lau et al, 2006) and the highest reported alpha coefficient was 0.98 (Gleaves et al, 1995; Bruce et al, 2007; Ko, Roh & Lee, 2020). All but two studies reported alpha coefficients of 0.8 or above. Only the study by Lau et al (2006) reported an alpha coefficient below the generally accepted minimum value for internal reliability ($\alpha = 0.7$). In fact, 144 of the 166 studies reported alpha coefficients of 0.9 or above and the spread of effects is arguably very small. Despite this, a substantial level of heterogeneity in the primary studies was observed ($tau^2 = 0.0009$, Higgin's $I^2 = 94.8\%$, $Q = 3164.14$, $p < 0.01$), suggesting that the estimates of alpha in the primary studies may be biased by the presence of uncontrolled or confounding factors. Therefore, the focus of the subsequent analyses will be upon the identification of the sources of heterogeneity between the estimates of alpha in the primary studies.

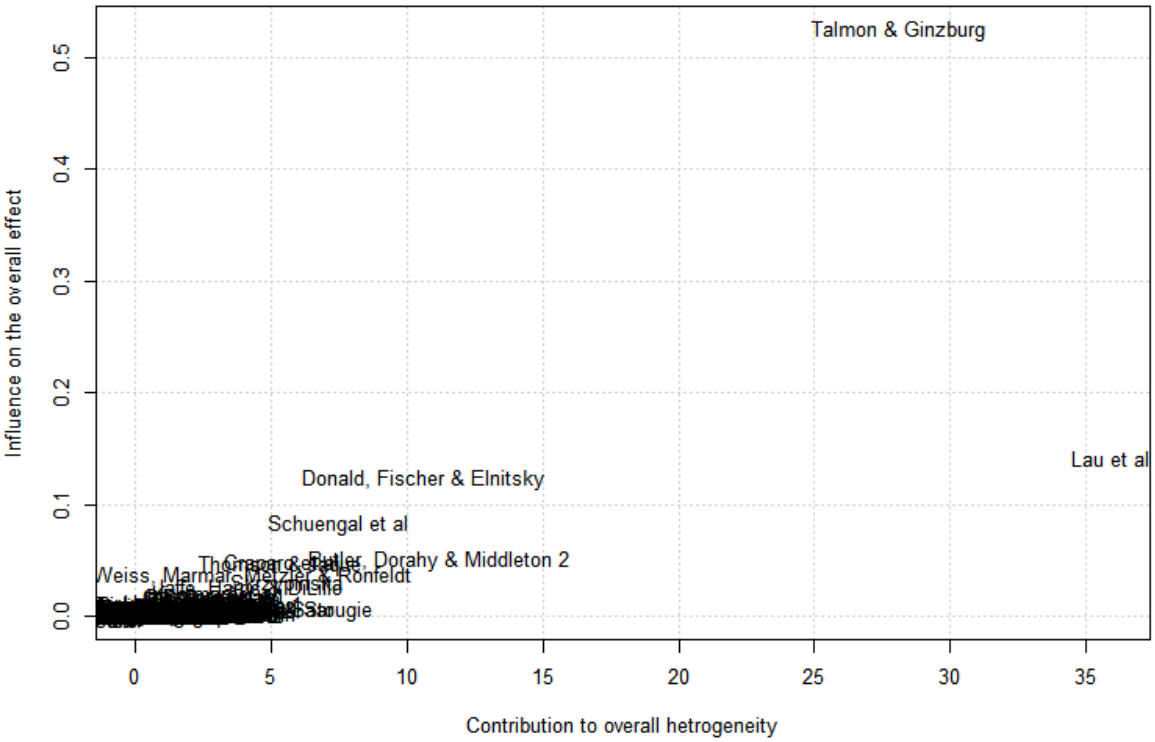
Figure 4: Forest plot of the Omnibus test for the Cronbach's Alpha



The impact of influential primary studies

The impact of disproportionately influential studies was assessed using a "leave-one-out" analysis. The random effects model was calculated with each of the primary studies removed in turn and the resulting change in weighted average effect size (i.e., influence) and the change in heterogeneity (i.e., discrepancy) was recorded. The results of this "leave-one-out" analysis is presented on the Baujat plot (Baujat, Pignon, & Hill, 2002) in Figure 5.

Figure 5: Baujat diagnostic plot of sources of heterogeneity. The vertical axis reports the influence of the study on the overall effect and the horizontal axis reports the discrepancy of the study with the rest of the literature.



Talmon and Ginzburg (2019) was identified as both influential and discrepant. The random effects model was recalculated with this study showing disproportionate influence removed. The adjusted random effects model reported a synthesis of $\alpha = 0.9291$ (95% CI 0.9247 to 0.9335). Higgin's I^2 showed a slight reduction to $I^2 = 94.4\%$. Therefore, no substantive change in conclusion is observed with the removal of this study.

One other study, Lau et al (2006), was identified as discrepant although not substantively influential on the overall effect. As a precaution, the random effects model was recalculated without this study. The adjusted random effects model reported a synthesis of $\alpha = 0.9284$ (95% CI 0.9236 to 0.9331). Higgin's I^2 showed a slight reduction to $I^2 = 94.7\%$. Therefore, no substantive change in conclusion is observed with the removal of Lau et al (2006).

Given their influence and discrepancy from the other literature, the Lau and Talmon studies were re-examined with regard to their appropriateness of inclusion in this review. Talmon and Ginzburg (2019) reported a very large sample of over 700 Hebrew speaking student participants from Tel Aviv University. The paper states that the DES-II was administered in an online format, but it provides no details of which language variant was used. It is therefore unclear whether the Hebrew version of the DES-II was used or if the original version was translated back and forth. Although this may represent a risk of bias, this study was not removed from the dataset as its removal did not have any substantial impact upon overall conclusions.

No clear reason for exclusion of Lau et al (2006) could be identified. Therefore, the studies by Lau et al (2006) and Talmon and Ginzburg (2019) were retained in the meta-analytic estimate.

The effect of risk of bias in the primary studies

In order to assess the impact of study level risk of bias upon heterogeneity, each type of methodological bias was explored. A subgroup analysis was conducted on the alpha for studies rated as "low risk" and "high risk". Statistical bias was not included due to the lack of variation in the rating of bias.

Table 4: Risk of bias in the primary studies

	Low Risk			High Risk				
	EFFECT	**95% CI**	**k**	**EFFECT**	**95% CI**	**k**	**X^2**	**P**
Selection bias	0.9331	0.9229; 0.9432	25	0.9276	0.9207; 0.9345	100	0.77	0.3806
Performance bias	0.9306	0.9215; 0.9396	30	0.9251	0.9148; 0.9355	44	0.59	0.4416
Detection bias	0.9320	0.9269; 0.9371	91	0.9327	0.9190; 0.9464	30	0.01	0.9238
Statistical bias	0.9454	0.9446; 0.9462	154	-	-	1		
Treatment Fidelity	0.9275	0.9205; 0.9345	87	0.9440	0.9216; 0.9664	7	1.90	0.1675
Generalisability bias	0.9266	0.9206; 0.9326	112	0.9420	0.9238; 0.9602	13	2.48	0.1154

There were not any statistically significant differences in the estimate of alpha between “low risk” and “high risk” in the methodological biases. This suggests that the ratings of methodological biases were not markedly contributing to the heterogeneity of the data.

The impact of study level differences

A series of subgroup analysis were conducted to further explore the impact of study level factors upon the internal reliability of the DES:

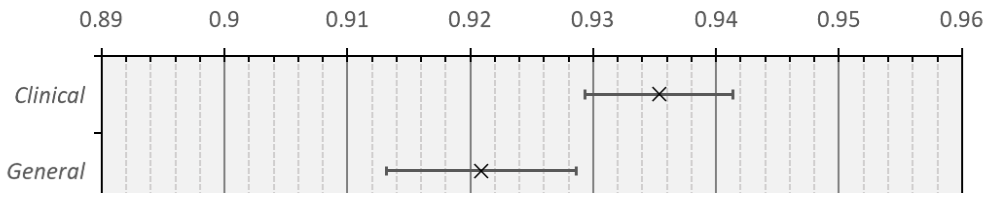
Table 5: Subgroup analysis

	Level	EFFECT	95% CI	k	X2	p
Scale version	DES	0.9293	0.9232; 0.9355	90	0.16	0.6916
	DES-II	0.9273	0.9192; 0.9354	67		
Sex ratio	Female >75%	0.9269	0.9184; 0.9355	70	0.85	0.3560
	Male >75%	0.9347	0.9206; 0.9488	15		
Sample	Clinical	0.9354	0.9293; 0.9414	61	17.57	0.0002
	General	0.9209	0.9132; 0.9286	89		

As can be seen from the table, there were not any significant differences in the estimates of alpha between the scale versions DES and DES-II. This suggests that the version of the scale used is not likely to have contributed to the heterogeneity of the data. There were also not any significant differences between the studies that had a majority male and a majority female in their samples, suggesting that this has not contributed to the heterogeneity of the data.

In comparison, a significant difference was reported for sample (X^2= 17.57, p<0.01) and the aggregated alpha value for each sample type is depicted Figure 6.

Figure 6: Aggregated alpha value for general and clinical sample



As can be seen in Figure 6, there was a significant difference between the general and the clinical samples. Although the general samples showed a significantly lower alpha coefficient, the figure is still comfortably above the minimum acceptable alpha coefficient of 0.7. A possible reason for the higher internal reliability in clinical samples is that the DES

was designed for a clinical use and consequently reflects the experience and symptomatology associated with clinical populations.

The impact of publication and small study biases

Publication bias is caused by the tendency for statistically significant results to be published and the reticence to publish papers with non-significant results. Small study bias is the tendency for studies with smaller sample sizes to show greater variability in their measurement of Alpha. To account for these study biases, Orwin's method (Orwin, 1983) was used to calculate the number of study's needed to be added to the meta-analysis for the overall effect to be reduced to a minimally interpretable value (Cronbach's Alpha 0.7). The number of studies required to reduce the meta analytic synthesis to less than 0.7 are described in Table 6.

Table 6: Orwin's method to calculate the number of study's needed to be added to the meta-analysis for the overall effect to be reduced to a minimally interpretable value

Average alpha reported in missing studies	Number of studies needed to reduce the meta-analysis effect to 0.7
0.65	755
0.6	378
0.55	252
0.5	189
0.45	151
0.4	126

Therefore, the alpha coefficient reported in studies lost to publication bias would have to be unfeasibly low to have had any substantial impact upon the conclusion of the current meta-analysis. Indeed, if the alpha coefficients reported in studies lost to publication bias was as low as alpha = 0.4 then 126 missing studies would be required to reduce the synthesis to below an alpha = 0.7. Therefore, this meta-analysis can be considered robust to the effects of publication bias.

Test/Retest reliability

Overview

There was a total of 12 primary studies involving a total of 1534 participants. The test/retest reliabilities described in these primary studies are reported in Table 7. Participants were selected from a variety of settings including veterans, general community, University students, forensic settings, and mental health settings. Participants varied in age, but in every study were adult participants over the age of 18. Country of origin and first language also varied throughout the studies, with five of the studies using a different language variant of the DES.

The test/retest coefficients are presented in table 7 and the weighted average effect was calculated using the fixed effects model. The fixed effects model weights the average by sample size and is preferable to the random effects model as the estimation of heterogeneity (e.g., as is required for the random effects model) is unreliable in small samples.

Table 7: Overview of test/retest primary studies

Study	Test/Retest Coefficient	Sample size	Version	Language Variant
Bizik et al (2011)	0.91	40	DES-II	Czek
Bob et al (2010)	0.91	58	DES-II	Czek
Bob et al (2015)	0.91	364	DES-II	Czek
Bob et al 2 (2010)	0.91	40	DES-II	Czek
Bernstein & Putnam (1986)	0.84	26	DES	English
Dubester & Braun (1995)	0.93	78	DES	English
Frischholz et al (1990)	0.93	30	DES	English
Putnam, Chu & Dill (1992)	0.78	83	DES	English
Sanders (1992)	0.79	46	DES	English

Svetlak (2010)	0.91	257	DES	English
Watson (2003)	0.66	465	DES-II	English
Chan, Fung, Choi & Ross (2017)	0.79	47	DES-II	Hong Kong

Selection of the meta-analytic model

The distribution of the study reporting test/retest reliability are shown in Figure 7.

Figure 7: QQ plot of the distribution of test/retest within the primary studies using the random effects model

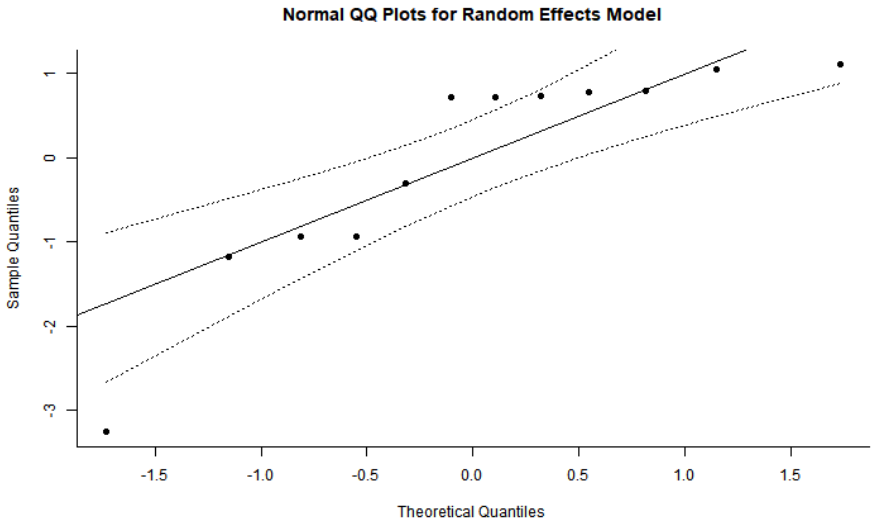
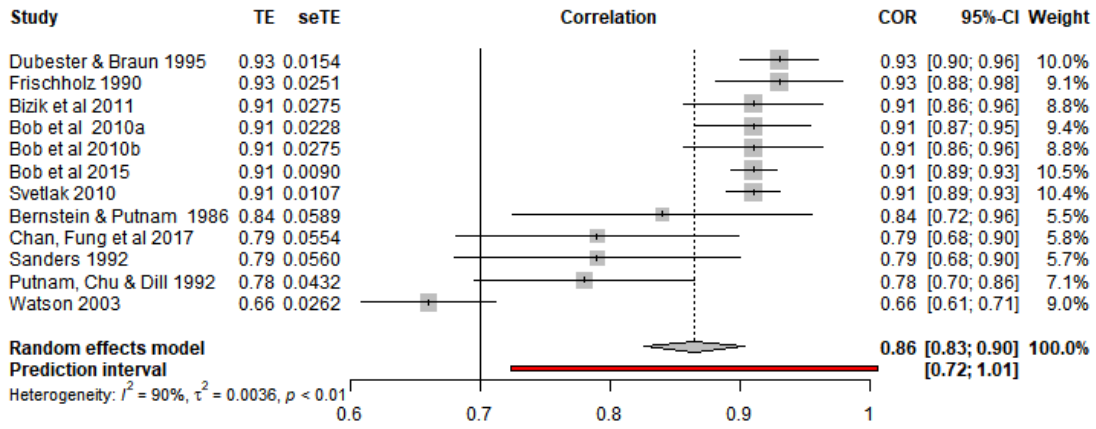


Figure 8 depicts the distribution of the study-level effects using the DerSimonian and Laird method of calculating between study variation (tau). The DerSimonian and Laird method is the most frequently used method for calculating the between studies variation (tau) when using the random effects model, however this estimator assumes that the effects sizes reported across each of the studies should approximate a normal distribution. Although some non-normality in the data remains, most of the primary study data falls within the 95% confidence intervals for the expected normal values and suggests that the use of the DerSimonian and Laird estimate is an appropriate method for the calculation of the variance of the true effect.

Synthesis of primary studies

A random effects model was calculated using the generic inverse variance method. The random effects model suggested a weighted average test/retest coefficient of 0.86 ($p < 0.001$) and a 95% confidence interval of between 0.83 to 0.90. A reliability coefficient of this size would be considered acceptable and is markedly greater than the generally accepted minimum test-retest reliability value of 0.70. According to more conservative estimations of acceptability, Portney & Watkins (2015) would rate a coefficient of 0.86 as "good".

Figure 8: Forest plot of the Omnibus test for the test/retest reliability



Level of heterogeneity

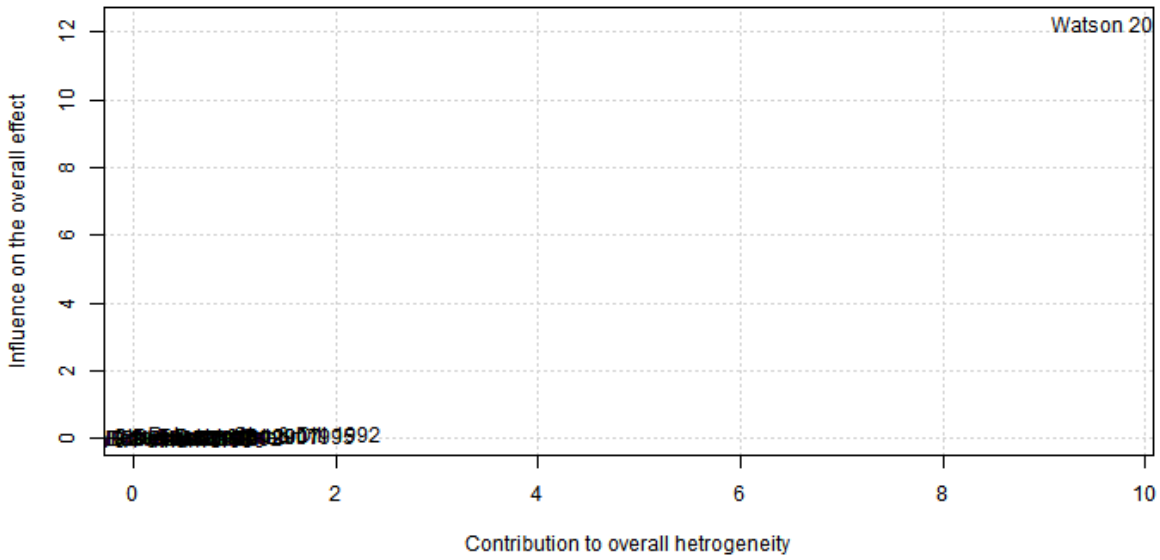
The lowest reported test/retest was 0.66 (Watson, 2003) and the highest reported test/retest was 0.93 (Dubester & Braun, 1995; Frischholz, 1990). All studies apart from one, reported test/retest of 0.75 or above. Only the study by Watson (2003) reported an alpha coefficient below minimum standard. Despite this, a substantial level of heterogeneity in the primary studies was observed ($tau^2 = 0.0036$, Higgin's $I^2 = 90\%$, $p < 0.01$), suggesting that the estimates of test/retest in the primary studies may be biased by the presence of uncontrolled or confounding factors.

The impact of influential primary studies

The impact of disproportionately influential studies was assessed using a "leave-one-out" analysis, in which the random effects model was calculated with each of the primary studies removed in turn and the resulting change in weighted average effect size (i.e., influence) and

the change in heterogeneity (i.e., discrepancy) was recorded. The results of this "leave-one-out" analysis is presented on the Baujat plot (Baujat, Pignon, & Hill, 2002) in Figure 9.

Figure 9: Baujat diagnostic plot of sources of heterogeneity. The vertical axis reports the influence of the study on the overall effect and the horizontal axis reports the discrepancy of the study with the rest of the literature.



One study, Watson (2003) was identified as both influential and discrepant. The study was reviewed with a view to its removal from the synthesis if reasons could be identified for the discrepancy between test/retest correlation report in this paper and that reported in the rest of the literature. However, no reason for its removal could be identified and therefore it has been retained in this study for synthesis.

As only a small number of studies were available only very limited conclusions can be drawn regarding test-retest reliability, however, the available data would suggest an acceptable level of reliability. Unfortunately, the relative paucity of studies reporting test-retest reliability obfuscated further exploration of heterogeneity.

Calculation of reliable change

Given a weighted average test-retest reliability of 0.86 then the retest values would need to be 5.61 points higher or lower than the initial test score in order to demonstrate reliable change at 66%, 10.99 points higher or lower than the initial test score in order to demonstrate reliable change at 95% confidence and 11.22 points higher or lower than the initial test score in order to demonstrate reliable change at 99% confidence.

DISCUSSION

The DES and its updated version, the DES-II, are the most commonly used measure of dissociation in practice and research. They have been used in a large number of research studies and their internal consistency has been reported to be high as measured by Cronbach's Alpha. Alpha values vary between studies, perhaps due to population size, sample type (normal or clinical), country or setting. The vast majority of studies fall in a descriptively small range of 0.8 to 0.98.

A previous meta-analysis has examined the validity and reliability of the DES (Van Ijzendoorn and Schuengel, 1996) but this is now outdated. To the authors knowledge there has not been an updated meta-analysis, or one which also examines the newer version of the DES. Van Ijzendoorn and Schuengel's (1996) meta-analysis demonstrated a weighted alpha coefficient of 0.93 for 16 studies. Given the importance of understanding and measuring dissociation based on its links with mental health conditions and childhood adversity and trauma, it is prudent to find a current aggregate alpha that takes into account methodological inadequacies and bias. 144 primary studies with 47,791 participants utilising the DES or DES-II showed a weighted alpha value of 0.93 (95% CI – 0.9236-0.9331). This alpha is well above the commonly acceptable minimum value of 0.7 and even when using more stringent criteria due to large sample sizes and a large number of test items, 0.93 remains a very high internal reliability value. Therefore, it could be concluded that the internal reliability for the DES and the DES-II variant is good. Furthermore, the alpha coefficient of 0.93 has remained consistent between van Ijzendoorn and Schuengel's (1996) meta-analysis and the current meta-analysis. This is despite the addition of 128 studies from across the globe with different language variants and inclusion of the DES-II. It is suggested, therefore, that the alpha coefficient of the DES is accurate and stable.

Little variation was observed in the alpha values when considering the following: publication bias, small study effects, quality rating effects and adjustments for heterogeneity and study influence. Alpha was not significantly impacted by version of the scale or proportion of gender of the participants. Interestingly, however, alpha was significantly impacted by the sample. General population samples had statistically lower (but still acceptable) alpha values than clinical samples. This may not be unsurprising, as the DES was designed for clinical populations, written based on experiences of people with dissociative disorders (Bernstein &

Carlson, 1986). The language, therefore, is likely to be less accessible for the general population and Carlson and Putnam (1993) argue that scores will be within a much narrower range. Sample size may have also had an influence with the general population samples often being large student sample studies. Although statistically different, the alpha value difference between the two is relatively small, and 0.92 would still be considered acceptable reliability by many standards. Even by the strictest of cut-offs, such as Bland and Altman (1997), who argue that for clinical application alpha coefficients should be 0.9 and above, 0.92 would be acceptable for use. To improve the internal reliability for the general populations, future research could explore understanding and adaption of items for people with little experience of dissociation. Despite a significant difference, the internal reliability only varied by 0.01, with both estimated alpha coefficients above 0.92. There is good evidence therefore that the measure has good internal validity in clinical and general population and varies only slightly between the two. It could be argued therefore that the DES is appropriate for measuring dissociation over time in situations where one might move between general and clinical levels of dissociation.

As stated, there was little variation observed in alpha coefficients between the DES and DES-II and this has been similarly reported in other reviews (Elliason et al, 1994, as cited in Ross, 1997). The current review found that authors often cited the original paper and version of the DES but then described the DES-II within the procedure. This inaccuracy in reporting is problematic, showing a large detection bias widely within the literature. However, as there is little difference in alpha coefficients between the different versions of the DES, the detection bias is unlikely to be affecting the overall quality of papers.

The high alpha coefficients found across all areas researched (version of the scale, gender, sample) suggest that the DES is generalisable and a good clinical indicator of dissociation. Studies for this meta-analysis spanned across many different countries of origin and included many different language variants (German, Finnish, Italian, Korean, Persian, Hebrew, Czech, Dutch, Spanish, Chinese, Swedish). As dissociation continues to be a focus for psychological research, the number of studies using the DES across the globe will continue to grow. Future research could improve the understanding of the generalisability of the measure by conducting discriminant analyses between language variants, countries and cultures. The current review was unable to do this due to there being too few papers.

Van Ijzendoorn and Schuengel's (1996) meta-analysis included a summary of 6 studies that quoted test/retest reliability between 0.78 and 0.93. This meta-analysis was able to considerably improve upon this review by doubling the number of papers included, allowing for calculation of a weighted average test/retest. There was a total of 12 primary studies involving a total of 1534 participants included in the meta-analysis, providing a weighted average test/retest of 0.86 ($p < 0.001$) and a 95% confidence interval of between 0.83 to 0.90. A test-retest reliability coefficient of this magnitude would be considered acceptable and it is markedly greater than the generally accepted minimum internal reliability value of 0.7. However, only a small number of studies were available for this review and therefore only very limited conclusions can be drawn.

Strengths and limitations

This meta-analysis provided an extensive exploration of heterogeneity and effects of bias. It has strengths because it is the first to explore the weighted alpha of the DES-II and compare it to the weighted alpha of the DES (of which there was found to be no significant difference). The analysis could have been stronger if this was extended to the other versions of the scale which are increasing in their popularity.

A limitation of the analysis is that some studies were not available to be included in the analysis for varying reasons including obtainability (15 studies) and the lack of resources to translate foreign languages. This may have impacted on the analysis, narrowing the generalisability of the results to countries that write their papers in the English language, despite the wide use of the DES in other countries and in other languages.

A wider limitation is that 461 studies that were identified as using the DES or DES-II did not include a calculation of internal consistency or test/retest and therefore could not be included in analysis. It was not feasible within this review to contact each of the authors for the alpha coefficient and/or test/retest, however, this missing data could have impacted on the analysis and the weighted alpha would have been more robust if the information was included.

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EMPIRICAL PAPER: CAN MEASURES OF DISSOCIATION, DEPRESSION, ANXIETY AND A MEASURE OF EFFORT AND ENGAGEMENT INCREASE THE PREDICTIVE VALIDITY OF DIAGNOSIS BETWEEN FUNCTIONAL MEMORY DISORDERS, DEMENTIA AND MILD COGNITIVE IMPAIRMENT

ABSTRACT

Rationale

Dementia diagnosis waiting times and rates of misdiagnosis are becoming an increasing challenge to the aging population. There is a national drive to reduce diagnosis times to six weeks but there are vast challenges to this including finding quicker and more effective ways to differentiate between Dementia, Functional Memory Disorder (FMD) and Mild Cognitive Impairment (MCI).

Method

The current study sought to investigate the predictive validity of psychometrics (Geriatric Depression Scale, Geriatric Anxiety Scale, Dissociative Experiences Scale and Somatoform Dissociation Scale) and an effort and engagement measure (Test of Memory Malingering) in differentiating between Dementia, FMD and MCI. A hierarchal linear regression was conducted to explore predictive factors of diagnosis, also including person characteristics, neurological factors and cognitive factors as collected as part of a standard memory assessment.

Results

Predictive factors of age, attending alone, ACE-III and depression all hold discriminant value between diagnoses. In particular, patients with FMD are younger than Dementia and MCI patients, have higher ACE-III scores than those with Dementia and are more likely to attend to alone than the other diagnoses.

Conclusion

There is preliminary evidence to support a phenotype of FMD which could be used to help create a screening measure in order to diagnose more effectively earlier in the pathway. This would reduce referrals to the memory clinics, ensuring a reduction in waiting times and a faster diagnosis and treatment pathway for all.

INTRODUCTION

It is estimated that there are 900,000 people in the UK living with dementia (Alzheimer Research UK, 2019). Dementia is characterised by acquired losses of cognitive ability and emotional ability which interfere with quality of life and daily functioning (Geldmacher & Whitehouse, 1996). Dementia is a progressive incurable illness but symptoms can be managed with psychosocial intervention and medication, depending on the type of dementia. It is, therefore, essential that patients are provided with accurate diagnoses in a timely manner. Accordingly, the Prime Minister's "2020 Challenge on Dementia" aims for dementia services to be diagnosing dementia within six weeks from a general practitioner (GP) referral (Department of Health and Social Care, 2016). In March 2020, an audit was published which explored the performance of memory services in five regions of NHS England (Dementia Clinical Network, 2020). The audit concluded that variations were noted in almost every part of the pathway, including assessment, investigation, diagnosis and treatment (Dementia Clinical Network, 2020). It found that clients waited for an average of 13 weeks from referral to diagnosis and this time varied dramatically between services from three to 36 weeks (Dementia Clinical Network, 2020). Overall, only 26% of patients were diagnosed within the six weeks of referral, with an average waiting time of five weeks for a brain scan alone (Dementia Clinical Network, 2020). The audit concluded that memory services need to consider how they can streamline services in order to work towards timely diagnosis. This is especially paramount with increasing rates of referrals. There is growth in demographics of those aged 85 and over with prevalence rates in this population thought to be approximately 30% (London Dementia Clinical Network, 2020). In addition, since 2020, the COVID-19 pandemic has increased waiting times further (Griffin, 2020).

How is Dementia diagnosed and what are the challenges to timeliness?

The usual pathway for referrals for dementia diagnosis is referral from General Practitioners (GPs) to a memory assessment service. Referrals are based on cognitive complaints coming from patient's self-report, other family member's concerns or presentation of cognitive difficulties in appointments booked for other reasons with GPs. As already stated, variations occur in all parts of the pathway (Dementia Clinical Network, 2020), but in general, memory nurses complete initial memory assessments with those referred and accepted to the service. Out of nine memory services that took part in the Dementia Clinical Network (2020) audit,

60% of patients were seen in clinic but this varied from 4% to 92% per service. The other patients were seen for their initial appointments at their place of residence.

In regard to assessment itself, there are several components with no singular component being considered on its own. A detailed history will be taken with information collected on onset and progression of cognitive difficulties, medications, vascular risk factors and impact on daily living (NHS, 2020). Cognitive testing will also be completed using one of the validated screening tools. Although numerous cognitive tests for dementia are available (NHS, 2020) the Addenbrooke's Cognitive Examination-III (ACE-III) is generally recommended as it's more detailed and has good diagnostic value with a cut-off score of 82 and less indicating a likely dementia (Hsieh et al, 2013). The ACE-III is not recommended however for those with established dementia with severe symptoms. The ACE-III has 21 questions and is scored out of 100, covering domains of Attention, Memory, Fluency, Language and Visuospatial. Although the most highly recommended screening tool, the ACE-III should not be used in isolation to make decisions on diagnosis. The ACE-III has better specificity when thresholds are much lower than the cut-off score and optimal thresholds for differential diagnosis are not fully understood (Beishon et al, 2019). In addition to the detailed history and cognitive testing, the initial assessment may also involve referrals for blood tests to rule out other medical problems and referrals for brain scans (NHS, 2020).

External waiting times for brain scans is a contributing factor to longer waiting times for diagnosis. NICE dementia guidelines (2018) suggest that structural imaging should be offered unless the dementia is well established, and the sub-type of dementia is clear. Due to excessive waiting times for scans, difficulties with access to scans (Dementia Clinical Network, 2020) and potential client disadvantages of scans such as discomfort and incidental findings, it is a reasonable expectation that services may want to reduce the number of scans offered. The increased pressure of scanning backlogs due to COVID 19 are also important in this regard. Therefore, currently there is a need to find other less time consuming assessments to help differentiate Dementia from other non-organic memory issues.

One recent study demonstrated that consistently over an eight-year period, over half of patients attending a cognitive disorders clinic were diagnosed with Functional Memory Disorder (FMD) rather than dementia or another neurological condition (Bharmabe & Larner 2018). Further guidance for neuroimaging for dementia states that brain scans should be

requested for younger people in the “absence of a significant mood or anxiety disorder or clinical features to suggest a functional cognitive disorder” (London Dementia Clinical Network, 2012). However, this does not follow the previously mentioned NICE guidelines (2018) which recommends brain scans except where certain of dementia and sub-type. It is easy to see how most people referred to the memory services would be referred for a brain scan, even where not necessary. Reducing the number of patients with FMD to memory clinic would reduce the number of brain scan referrals and thus reduce the waiting times. In addition to unnecessary brain scanning, neuropsychologists are presented with FMD in ranges from 20 to 40% (Greiffenstein et al., 1994; Frederick, 2000; Green, Rohling, Lees-Haley, & Allen, 2001; Mittenberg, Patton, Canyock, & Condit, 2002). A person with FMD may perform poorly on validated measures due to attention and effort, leading to a false positive result. Additionally, neuropsychology assessments are timely.

The Dementia Clinical Network (2020) found that overall 67% of patients over the age of 65 were diagnosed with dementia and 18% of people were diagnosed with a Mild Cognitive Impairment (MCI). MCI has become a more common diagnosis over time as people have more knowledge of Dementia and present earlier with concerns about their memory. MCI is considered to be a prodromal phase associated with brain disorders, including dementia (Larner, 2016; de Mendonça, 2004). In general, MCI has a heterogeneous population with characteristics of objective cognitive impairment but not to the extent of dementia and without progression or impact on daily living skills (London Dementia Clinical Network, 2020).

It appears that a significant number of individuals attending for cognitive assessments within services do not have dementia despite reporting significant cognitive symptoms. In fact, a review by McWhirter, Ritchie, Stone and Carson (2020) suggests that cognitive symptoms are estimated for a third of the population and have no correlation to age. The diagnosis a person receives depends on the memory service where they are being assessed with huge variations in the types of diagnosis provided between services (Dementia Clinical Network, 2020). The variation in diagnoses highlights the rates of misdiagnosis. In addition to misdiagnosis between Dementia and FMD, Stone et al (2015) argues that significant numbers of clients with FMD are diagnosed with MCI. Misdiagnosis might mean that clients are not offered the correct medications and with the emergence of disease-modifying treatment, accurate diagnosis will become of greater importance. Schmidtke and colleagues (2008)

conducted a review which suggests that FMD is not a benign condition, with follow up data suggesting that symptoms are largely persistent over time and thus they too require specialised care and treatment.

It appears that standard memory assessments are firstly not very successful in differentiating between FMD and non-functional memory problems and secondly rely on measures of assessment such as brain scanning and neuropsychology reports which take up valuable resources, adding to wait times. If one wants to reduce wait times and increase accuracy of diagnosis, further understanding of FMD and how it differs from non-functional memory diagnoses of dementia and MCI is needed.

What is a FMD?

FMD are usually related to combination of factors that impact on concentration and attentional ability. These include chronic pain conditions, sleep disorders, polypharmacy, mental health conditions, somatoform disorders and cogniform conditions (Delis & Wetter, 2007). There is not a widely agreed definition for FMD. For the purpose of this research, Stone and colleagues (2015) definition will be used. They describe FMD as "memory problems with no neurological disease process" and this umbrella diagnosis includes many categories of memory problems which are described in the table below.

Table 1: Categories of memory problems in FMD

1	Cognitive symptoms as part of anxiety or depression
2	"Normal" cognitive symptoms that become the focus of attention
3	Isolated functional cognitive disorder in which symptoms are outwith "normal" but not explained by anxiety
4	Health anxiety about dementia
5	Cognitive symptoms as part of another functional disorder (e.g. somatoform disorder)
6	Retrograde dissociative (psychogenic) amnesia
7	Cognitive symptoms secondary to prescribed medication or substance misuse
8	Diseases other than dementia causing cognitive disorders
9	Exaggeration/malingering

FMD and the differences to Dementia

Effort and engagement

Current literature on FMD (and its different types) can be drawn upon to help aid the process of differentiation between FMD and non-functional impairments. In the past 20 years, over 300 studies have focused on cognitive complaints such as memory and concentration which are not related to neurological deficit (see reviews by Iverson & Binder, 2000; Hom & Denney, 2002; Larrabee, 2005). As stated previously, people with FMD can perform poorly in cognitive testing. Jansen and colleagues (2017) found evidence to suggest that in 221 patients attending memory clinics, neuropsychological assessment did not improve dementia classification and increased false positive diagnosis for those with subjective cognitive impairment. Neuropsychological assessment within FMD has therefore focused on measuring effort as a means of understanding symptoms of exaggerating cognitive testing. It is difficult for clinicians to objectively assess whether or not malingering symptoms are intentional or unintentional (Panktraz & Erickson, 1990; Rogers, 1990a,b; Trueblood & Binder, 1997; Slick et al., 1999). Many individuals who exhibit these cognitive problems may not themselves be aware of whether or not their intentions are conscious or unconscious. Dellis and Wetter (2007) have suggested the use of "Cogniform Disorder" to describe performance that shows excessive cognitive symptoms but does not show evidence of intention to warrant a Malingering diagnosis. It is also important to consider that a person's cultural background may influence denial of symptoms or exaggeration of symptoms without conscious or unconscious motivation (Bush et al, 2005). Even when neuropsychological tests have been validated for a majority culture, minority culture may impact on the validity (Bush et al, 2005).

For individuals that intentionally or non-intentionally exhibit excessive cognitive symptoms, performance in measures of effort is poor (Dellis & Wetter, 2007). Poor performance in tests of effort shows difference from those with differential diagnoses of dementia who tend to pass measures of effort (McGuire, Crawford & Evans, 2019). The Test of Malingering Memory (TOMM) is one such measure of effort. Across studies that examined the specificity of the TOMM in dementia samples with a cut-off score of below 45, figures have ranged from 82% (Trial 2, Greve et al, 2006) to 24% (Trial 2, Teichner & Wagner, 2004). In a paper by Dean et al (2009) it is concluded that specificity remains over 90% when cut-offs are altered to slightly higher than 50% correct (Trial 2 = 28). A later paper by Walter, Morris,

Swier-Vosnos & Pliskin (2014) found that the differences in specificity across papers is likely due to differences in cognitive functioning in samples. Their paper found evidence to suggest that cognitive functioning has a positive correlation with performance in Trial 2. If one has severe cognitive impairments, they are less likely to pass (Walter et al, 2014). Tests of effort, therefore, may be worth exploring to see if they hold discriminant value between functional and non-functional memory disorders, especially where dementia is in its earlier stages.

Memory clinic reviews

Many reviews (Stone et al, 2015; Bailey et al, 2018; London Clinical Networks, 2020) have sought to collate information from memory clinics to find subtle differences that may exist between patients diagnosed with dementia and FMD. Each review found that those with FMD were more likely and able to attend their memory appointment alone. Stone and colleagues (2015) and London Clinical Networks (2020) reviews also suggested that patients were likely to be younger and more inconsistent when reporting their cognition in comparison to those with dementia. An audit by London Clinical Networks (2020) found that across nine memory services 84% of patients seen under the age of 65 did not have dementia. Bailey and colleagues (2018) review suggested that patients with FMD were more likely to offer detailed descriptions of complaints and less likely to turn to a family member for support when asked questions. It appears that a person's age, self-report of cognitive problems and whether or not they attend their initial assessment alone might provide useful in helping to differentiate FMD.

Psychometrics

McWhirter and colleagues (2019) review included a diverse range of studies that suggested a broad functional cognitive disorder phenotype. They found that depressive symptoms were the most common association and this is echoed in other reviews (Reid & Maclullich, 2006; Hill et al, 2006). A study by Matternich, Schmitdtke and Hull (2009) also evidenced elevated depression scores, which are pathological, in FMD in comparison to the general population. Prevalence of depression in dementia is also reported to be high, between 20 and 60% (Steffens et al, 2006; Tsuno & Homma, 2009), increasing with the severity of dementia (Forsell & Winblad, 1998; Rubin et al, 2001). Dementia's relationship with depression has

been shown to be complex. There is a body of evidence which suggests depression may be a risk factor for the development of dementia (Speck et al, 1995; Jorm, 2001; Green et al, 2003; Geerlings et al, 2008). Depression may also be a reaction to the development of cognitive decline in dementia (Ganguli, 2009). Complicating matters further, apathy is a neuropsychiatric symptom which can be a feature of Dementia and depression and distinguishing its presentation as one or the other can be difficult. This is especially true when considering evidence to suggest that self-reported depression varies considerably in Dementia populations due to deficit awareness (Snow et al, 2005) and has historically been viewed as inaccurate (Simmons et al, 1997). It may be that patients with Dementia perform differently to patients with FMD in self-report measures of depression. Although prevalence is thought to be high in both population groups, there are subtle differences in presentation which may impact on self-reported scores. For example, rates of nondysphoric depression is more commonly observed in Dementia (Panza et al, 2010) and are likely to present differently to standard depression in self-report measures. In addition, patients with dementia presenting at the memory clinic are more likely to be in early stages of Dementia and may therefore have lower depression scores than FMD. It is also possible that deficit awareness and the suggested variability in depression amongst Dementia patients shows a significant difference to those with FMD. It might be therefore, that self-reported depression could help to differentiate between FMD and Dementia.

The McWhirter et al (2019) review also found that anxiety symptoms and personality traits such as neuroticism were frequently associated with subjective cognitive impairment. It appears that exploring a person's mental health may therefore be an important part of differentiating between FMD and Dementia in addition to considering their age, self-reported memory problems and attendance alone or accompanied. Anxiety in particular is thought to have a close relationship with depression (Knowles & Olatunji, 2020) and may hold discriminant value between FMD and Dementia.

In FMD, emotional blunting, stress and dissociation are thought to be key features. Emotional blunting is a symptom common to both FMD (Schmidtke, Pohlmann & Metternich, 2008; Blackburn et al, 2014) and differential diagnoses of dementia, especially frontotemporal dementia due to executive functioning deficits (Joshi et al, 2014; Mendez et al, 2006). Once again this highlights how easy it can be to misdiagnose. Dissociation, on the other hand, may offer a way to explore differences between FMD and dementia diagnoses. Dissociative scales

such as the Dissociative Experiences Scale have been shown to have discriminant validity between patients experiencing dissociative symptoms and other forms of psychopathology (Bernstein & Putnam, 1986). Features of dissociative conditions include memory gaps and depersonalisation. The cause of such symptoms is thought to be due to dysregulation of the autonomic system due to the experience of prolonged psychological trauma (Van Der Kolk, 2014). Long term stress has also been implicated in the development and persistence of FMD (Schmidtke et al 2008), indicating a potentially similar pathway in the aetiology of dissociative conditions and FMD. Currently no study has looked at the relationship or predictive validity of dissociation in the differential diagnosis of dementia from FMD.

In summary, memory services are faced with finding a way to reduce their waiting times for diagnosis. Waiting times are lengthy partially due to large numbers of people with FMD being referred to memory services and the associated difficulties with differentiating between this presentation and the presentation of dementia or MCI. Literature on FMD is relatively vast and indicates possible ways to help differentiate between diagnoses. For example, reviews have suggested that patients with FMD tend to be younger and attend appointments alone. Additionally, patients with FMD have been found to have higher rates of depression and anxiety than the general population and tend to fail measures of effort. Lastly, dissociation can be closely linked with mental health problems and difficulties with cognition and may provide a way to differentiate between FMD and dementia.

Aims of current study

The current study has the following aims:

The aim of this project is to understand whether neurological (Dementia and MCI) and functional memory problems can be differentiated based on effort and engagement (effort test scores) and psychological characteristics (depression, anxiety, dissociation, history of psychological trauma). Therefore, this research examines whether results of effort tests and psychological characteristics offer greater predictive value for differential diagnosis over and above factors collected as part of a usual memory assessment. A usual memory assessment includes: personal characteristics (age, gender, attendance alone or accompanied), cognitive characteristics (ACE-III score) and neurological characteristics (brain scan abnormality, vascular risks).

The current study also aims to understand which of these factors, if any, have the most discriminant validity in predicting diagnosis.

Hypothesis

The study hypothesises that psychological characteristics and effort and engagement factors will improve the predictive validity of diagnosis above and beyond the model based on a standard memory assessment.

The null hypothesis is that the psychological characteristics and engagement factors will not have predictive validity in the model.

METHOD

Design and Data Analysis

The first step of data analysis was to explore group differences.

Discrete independent variables (age, ACE-III score, TOMM trial 1 and 2 score, GDS score, GAD score, DES-II score and SDS score) were assessed with the dependant variables (MCI, Dementia, FMD) using a between groups pairwise test of the equality of column means.

Categorical data independent variables (gender, TOMM trial 2 fail, self-reported memory, psychological trauma, vascular risk factors) were assessed using a two-sided chi-square analysis with the dependant variables (MCI, Dementia, FMD).

The second step of data analysis was to use a hierarchal linear regression to analyse the relationship between predictor variables and the response variable. Predictor variables were categorised into the following groups: participant characteristics (age, gender, attendance alone/accompanied), neurological factors (vascular risk factors, brain scan abnormalities), cognitive factors (ACE-III score, self-reported memory problems), effort and engagement (TOMM score and TOMM trial 2 pass/fail) and psychological factors (psychological trauma, GDS score, GAS score, DES-II score and SDS score).

The first hierarchal linear regression explored predictor factors that distinguish between Dementia and FMD. The second hierarchal linear regression explored predictor factors that distinguish between MCI and FMD. A forward stepwise logistic regression was then calculated with the factors shown to significantly impact the model in order to explore the minimum model and its predictive validity.

Ethics

Ethical approval for the current study was provided by the Cornwall and Plymouth Research Ethics Committee. The Health Research Authority and Health and Care Research Wales (HCRW) approval letter was dated 11th May 2020 (Protocol Number: 273569; REC Number 20/SW/0070; Appendix 2).

Participants were approached at their initial memory assessment by the memory nurse and provided with an information sheet (Appendix 3) and a consent to contact form (Appendix 4). They were given sufficient time to review the information prior to arranging a meeting to give consent (Appendix 5). For information on data protection, please review the participant information sheet (Appendix 3) and for information on potential distress and support offered, please review third party mental health support document and letter to the GP (Appendix 6 & 7).

Recruitment

Recruitment took place across the Black Country Healthcare NHS Foundation Trust in several sites including Sandwell, Walsall and Wolverhampton. Potential participants were first approached by local clinical collaborators at their initial memory assessment. During this appointment they were provided with study information (participant information sheet) and asked whether they would like to be contacted by the chief investigator for further information. If they did want to be contacted, they were provided with and asked to sign a consent to contact form. The chief investigator (Chloe Herrick) then contacted the consenting individuals 48 hours later to provide more details about the research and ask them if they would like to participate in the study. If they wanted to participate and they met the eligibility criteria, a date, time and place (memory clinic, home address or GP office) was arranged for the research to take place. The study was conducted at the participant's choice of location.

Inclusion and exclusion criteria are shown in Figure 1. Individuals were required to have self-reported or carer/relative reported memory problem which had prompted a memory assessment. Individuals should be over the age of 45 as memory complaints in individuals under the age of 45 are rare and therefore clinically different (Rossor et al, 2010). Additionally, persons should be under the age of 100.

Figure 1: Inclusion/exclusion criteria

Inclusion criteria	Exclusion criteria
The person must have been referred to the memory services for a self-reported or carer/relative reported memory problem	The person does not complain of a memory problem and one is not evident through assessment

The person should be over the age of 45 and under the age of 100	The person is not able to engage in formal measure (the dementia is too far progressed)
	Must not have a known current substance abuse problem
	Must not have recently been involved in a memory or mental-health based research project

Due to the limitations resulting from the research sponsorship there are currently no resources available to support the recruitment of individual whose first language is not English. For those where language is a barrier, it is hoped that the participant will have a friend, family member or NHS staff member who can act as an interpreter, and in this instance, the researcher can arrange to meet with them to assist with describing the study, obtaining consent and completing the study.

For anyone with a specific language need (due to their specific memory complaint) adaptions will be made. For example, questionnaires might be read to participants if their specific memory complaint means that they are unable to read or write.

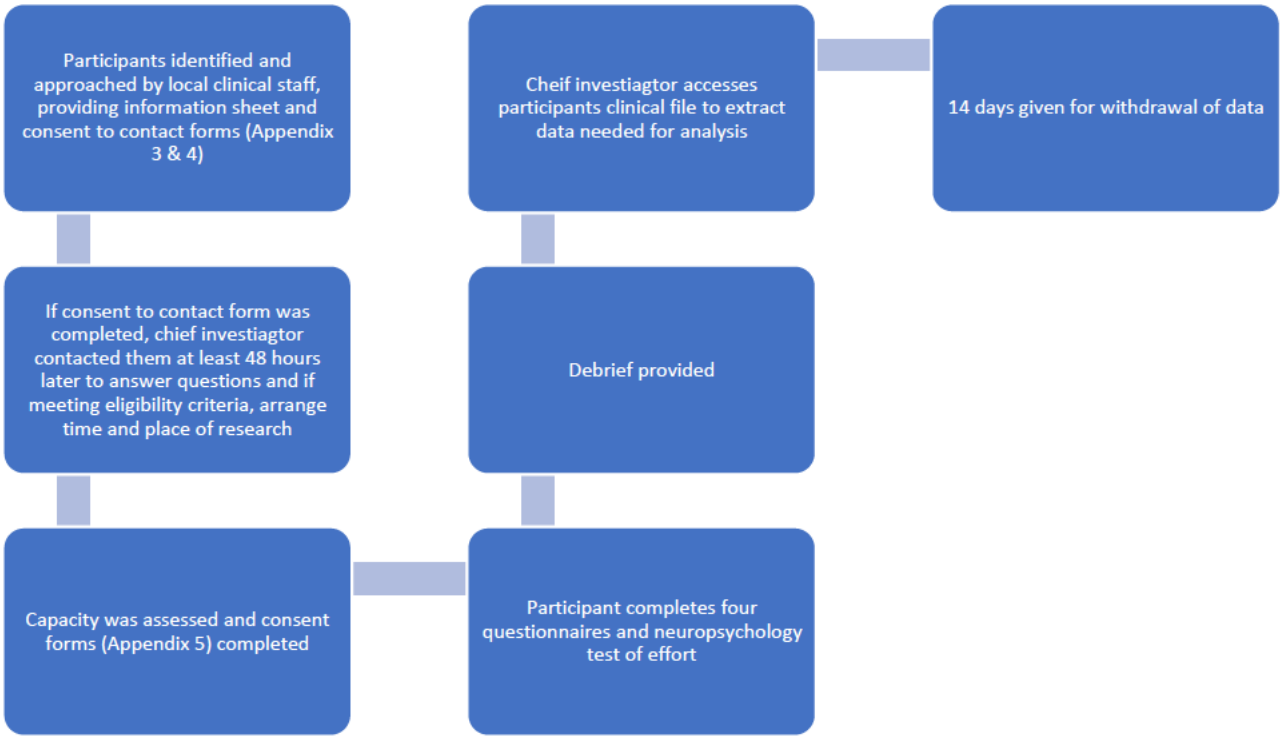
Participants

The participants included 42 people (21 females and 21 males) between 48 and 90 years old, recruited from the memory service. Participants were all fluent in English. There were 37 White British participants, two Black British participants and three Indian British participants. The number of years participant's spent in education ranged between 10 and 20.

Procedure

Participation in the study involved an estimated 60 minutes of the participant's time. A summary of the procedure can be seen in Figure 2, showing how participants were recruited and how they participated in the study.

Figure 2: Procedure flow chart



Determining capacity to consent

Prior to participation in the study, each participant was asked to recall the purpose of the study and what participating would involve. Due to the nature of the client's memory problems, prompts were provided if needed (e.g. do you recall that the research means you are going to complete some questionnaires?). If a participant was able to show that they had awareness of the research process and purpose and could consider their involvement, they were considered able to adequately show capacity to consent.

Measures

Participants were asked to complete four self-report questionnaires independently or with support from the researcher, depending upon their preference and level of need.

Self-report Questionnaires

Geriatric Depression Scale short version (GDS; Sheikh & Yesavage, 1986)

This self-report measure consists of 15 items requiring "yes" or "no" answers based on how the person has been feeling over the past week. The measure aims to screen for depression in older adults. Scores can vary from zero to 15. Scores zero to four indicate no cause for concern, five to eight suggest mild depression, nine to 11 suggest moderate depression and 12 to 15 suggest severe depression. To score the GDS, answers in **bold type** emphasise significance to depression and should be given a score of one. 10 of the "yes" responses and five of the "no" responses are in bold type. If participants chose to complete this measure independently, they were provided a copy of the measure which does not have answers in bold so that their responses were not influenced. The GDS has demonstrated moderate reliability. Friedman and colleagues (2005) report internal consistency of $\alpha = 0.749$ in their study of 960 adults aged 65 and older. This study also suggested that the reliability and validity of the GDS did not differ significantly between older adults who had high or low functional impairment (Friedman et al, 2005). This suggests that the measure can be used confidently with older adults who have varying levels of functioning. Additionally, the GDS has been found to have no clinically significant differences in test performance based on age (including a population under 65), gender, ethnicity and comorbidity (Nyunt, Fones, Niti & Ng, 2009).

Geriatric Anxiety Scale short version (GAS-10; Mueller et al, 2014)

The GAS-10 is a self-report assessment designed for use in older adults to screen for anxiety. Participants are asked to rate 10 items which describe symptoms of anxiety on a Likert scale which ranges from zero (not at all) to three (all of the time). Scores range from zero to 30, with higher scores indicating more severe anxiety. Scores one to six indicate "minimal" anxiety, seven to nine indicate "mild" anxiety, a score of 10 indicates "moderate" anxiety and 12 to 30 indicates "severe" anxiety (Segal et al, 2010). According to Mueller and colleagues (2014) the measure has good internal consistency ($\alpha = 0.89$). Although created for a geriatric population over the age of 65, evidence suggests that the GDS has comparable validity in younger populations also (Weintraub, Saboe & Stern, 2007).

Dissociative Experiences Scale II (DES II; Carlson & Putnam, 1993)

The DES II is a self-report measure consisting of 28 items aiming to measure the frequency of dissociative experiences in a person's daily life. It measures a wide range of dissociation including normal dissociative experiences. Participants are asked to consider what percentage of the time they experience dissociative features by circling one of eleven options starting from 0% and rising by 10% to 100%. The DES-II score is an average of all the questions with scores ranging from zero to 100. Scores of 30 and more are thought to indicate high levels of dissociation. Zingrone & Alvarado (2001) found the measure has good internal consistency (α = .92) in a study with a general population.

Somatoform Dissociation Scale (SDQ-20; Nijenhuis et al, 1996)

The SDQ-20 aims to measure the severity of somatoform dissociation. Participants are asked to rate 20 items which relate to dissociative phenomena on a five point Likert scale ranging from one (this applies to me NOT AT ALL) to five (this applies to me EXTREMELY) based on their experiences in the past year. The questionnaire asks about bodily and physical symptoms which may have been experienced briefly or for a long time. Participants are also asked to state if the experience has been connected by a physician to a physical disease. Scores range from 20 to 100 and is calculated by the sum of the individual item scores. Scores over 30 are thought to indicate somatoform dissociation. The scale has good internal consistency α = 0.95 (Nijenhuis et al, 1996) and satisfactory test-retest reliability (Sar et al, 2000). Nijenhuis (2003) found that the scale is not affected by age, indicating that the scale is appropriate for use with older adults.

Neuropsychology effort test

Participants completed a neuropsychology effort test, administered by the researcher according to the manual's standardised instructions.

Test of Memory Malingering (TOMM; Tombaugh, 1996)

The TOMM is a visual recognition test that aims to distinguish between malingered and true memory problems. The TOMM includes two learning trials and an optional retention trial. All trials were administered in a standardised manner based on the manual. The learning trials consist of a study and test phase. The study phase of each learning trial has 50 targets (line drawn pictures of everyday items) which are each presented for three seconds. During the test phase, each target is paired with a distractor (different line drawing). The position of the target is counterbalanced for top and bottom positions. The retention trial was completed 10 minutes after the completion of the two learning trials and consists of a test phase only. A score of 50 can be obtained in Trial 1 and 2, giving a maximum overall score of 100. Low scores indicate possible exaggeration of memory problems, with 44 points or less typically used as a cut-off score to indicate conceivable malingering (Love, Glassmire, Zanolini & Wolf, 2014).

RESULTS

Group differences

As stated earlier, variables were grouped into participant characteristics, neurological factors, cognitive characteristics, effort and engagement and psychological factors. The table below shows descriptive statistics for all variable and group differences for discrete data.

Table 2: Group differences

			Diagnosis		
			Dementia	FMD	MCI
Participant characteristics					
Age	Mean		76.25_a	63.17_b	74.63_a
	Standard Deviation		12.63	10.22	11.35
Gender	Female	Count	10	8	3
	Male	Count	6	10	5
Attended alone	Unaccompanied	Count	1	9	0
	Accompanied	Count	15	9	8
Neurological Factors					
Brain Scan	CT	Count	4	2	1
	CT & MRI	Count	0	3	1
	MRI	Count	11	5	3
	MRI & DAT	Count	0	1	1
	None	Count	1	7	2
Scanning Abnormality identified	No	Count	5	8	3
	Yes	Count	10	3	3
Vascular risk	No Risk	Count	1	10	1
	Risk identified	Count	15	8	7
Cognitive characteristics					
Self-reported memory difficulties	No	Count	10	3	3
	Yes	Count	6	15	5

			Diagnosis		
			Dementia	FMD	MCI
ACE-III	Mean		64.00_a	82.81_b	83.25_b
	Standard Deviation		15.78	9.51	8.53
Effort and engagement					
Trial 1	Mean		40.44_a	43.39_a	46.13_a
	Standard Deviation		5.23	6.04	5.59
Trial 2	Mean		43.81_a	47.44_a	49.25_a
	Standard Deviation		6.41	5.12	1.16
TOMM_Trial_2_Fail	Pass	Count	9	16	8
	Fail	Count	7	2	0
Psychological characteristics					
History of psychological trauma	No	Count	13	6	8
	Yes	Count	3	12	0
Depression	Mean		4.44_a	10.22_b	2.75_a
	Standard Deviation		5.15	4.41	1.83
Anxiety	Mean		4.44_a	14.28_b	2.13_a
	Standard Deviation		5.83	7.97	1.96
Dissociation	Mean		6.89_a	27.65_b	4.78_a
	Standard Deviation		11.19	16.50	4.31
Somatoform	Mean		24.75_a	34.72_b	21.88_a
	Standard Deviation		8.52	9.99	2.85

Note: Values in the same row not sharing the same subscript are significantly different at $p < .05$. Tests are adjusted for all pairwise comparisons within a row of each innermost subtable using the Benjamini-Hochberg correction

Participant Characteristics

Age

The mean age of patients diagnosed with a dementia was 76 and the mean age of patients diagnosed with an MCI was 75. These two means significantly differed from the mean age of patients diagnosed with FMD (mean age = 63). The patients diagnosed with FMD had a mean average age that was over 10 years younger than the other two diagnosis groups.

Cognitive Characteristics

ACE-III

Patients with dementia had mean ACE-III scores that were significantly lower than the FMD and MCI diagnosis groups. Those with dementia had a mean ACE-III score of 64 (sd = 15.78) in comparison to a mean ACE-III score of 83.25 (sd = 8.53) for those with MCI and 82.81 (sd = 9.51) for those diagnosed with FMD.

Effort and Engagement

Trial 1 and Trial 2 of the TOMM

There were no significant differences between the diagnostic groups in mean score on trial 1 or trial 2 of the TOMM.

Psychological Factors

Depression

Mean scores on the GDS significantly differed between FMD and the other two diagnosis groups. Mean depression scores were much higher for those diagnosed with FMD (10.22, sd = 4.41) in comparison to lower scores for those diagnosed with dementia (4.4, sd=5.15) and MCI (2.75, sd=1.83).

Anxiety

Mean anxiety scores on the GAS were significantly higher for those diagnosed with FMD (14.28, sd = 7.97) in comparison to lower scores for those diagnosed with dementia (4.44, sd =5.83) and MCI (2.13, sd = 1.96).

Dissociation

Mean dissociation scores on the DES-II were significantly higher for those diagnosed with FMD (27.65, sd=16.5) in comparison to lower scores for those diagnosed with dementia (6.89, sd= 11.19) and those diagnosed with MCI (4.78, sd = 4.31).

Somatoform

Mean somatoform dissociation scores on the SDS were significantly higher for those diagnosed with FMD (34.72, sd=9.99) in comparison to those diagnosed with dementia (24.75, sd=8.52) and those diagnosed with MCI (21.88, sd=2.85).

Group differences for categorical variables

Probabilities of Chi-square tests were calculating using Fisher's Exact Method.

Gender

There was no difference in the proportion of males and females in each of the diagnostic categories ($X^2 = 1.722$, $p = 0.48$).

Attended alone

There was a significant difference in the proportion of patients that were accompanied or unaccompanied in each of the diagnostic categories ($X^2 = 12.026$, $p = 0.002$). Only one patient with dementia attended alone and none of the patients with MCI attended alone. In comparison, half of the patients (9) diagnosed with FMD attended alone.

Vascular risk factors

There was a significant difference in the proportion of patients that had vascular risks or did not have vascular risks in the diagnostic categories ($X^2 = 11.341$, $p = 0.003$). Out of the 16 patients diagnosed with dementia, all patients but one had vascular risk factors. Similarly, out of the 8 patients diagnosed with MCI, only one patient was found to not have vascular risks. In comparison, 10 out of the 18 patients with FMD did not have any vascular risks.

Self-reported memory difficulties

There was a significant difference in the proportion of patients who answered yes to the statement on the GDS ("Do you feel that you have more problems with memory than most?") between each of the diagnostic categories ($X^2 = 7.547$, $p = 0.018$). Patients diagnosed with dementia were more likely to answer no (10 out of 16 patients answered no). In comparison, patients diagnosed with FMD were more likely to say yes, (15 out of 18 answering yes). For those diagnosed with MCI, 5 out of 8 of the patients stated yes.

TOMM Trial 2 Fail

There was a significant difference in the proportion of patients who failed and passed the TOMM trial 2 in each of the diagnostic categories ($X^2 = 8.055$, $p = 0.017$). For the MCI group, no patients failed. In comparison, 2 out of 18 patients with FMD failed and 7 out of 16 dementia patients failed.

History of psychological trauma

There was a significant difference in the proportion of patients who reported a history of psychological trauma between the diagnostic categories ($X^2 = 13.961$, $p = <0.001$). Most patients diagnosed with FMD (12 out of 18) stated that they had experienced psychological trauma in comparison to most patients diagnosed with dementia stating that they had not experienced psychological trauma (13 out of 16). None of the patients with MCI stated that they had experienced psychological trauma.

The differentiation of Dementia and FMD

A hierarchical logistic regression was undertaken in order to identify factors that distinguish between a diagnosis of Dementia and FMD. Participants with MCI were removed from the analysis, leaving 33 participants. The predictor variables were entered in five blocks as indicated below:

Block 1: Participant Characteristics = Age, Gender and Attended alone
Block 2: Cognitive Characteristics = Self-reported memory difficulties
Block 3: Neurological factors = Scanning Abnormality identified, Vascular risk
Block 4: Psychological Factors = History of psychological trauma, Depression, Anxiety, Dissociation, Somatoform Dissociation
Block 5: Effort and Engagement = TOMM Trial 1, TOMM Trial 2, TOMM Trial 2 Fail

The goodness-of-fit chi-square was calculated at the addition of each of the blocks to the predictive model. The goodness of fit associated with the addition of each of the blocks and for all variables within the model is presented in the table below:

Table 3: Goodness-of-fit Chi-square for each block of variables added to the model

	Variables added to the model	Block Chi-square (p)	Model Chi-square (p)
Block 1	Age, Gender and Attended alone	17.527 (<0.001)	17.527 (<0.001)
Block 2	Self-reported memory difficulties, ACEIII	11.299 (0.004)	28.826 (<0.001)
Block 3	Scanning Abnormality identified, Vascular risk	1.046 (0.593)	29.871 (<0.001)
Block 4	History of psychological trauma, Depression, Anxiety, Dissociation, Somatoform	11.584 **(**0.041**)**	41.455 (<0.001)
Block 5	Trial 1 TOMM, Trial 2 TOMM	0.00 (0.999)	41.455 (<0.001)

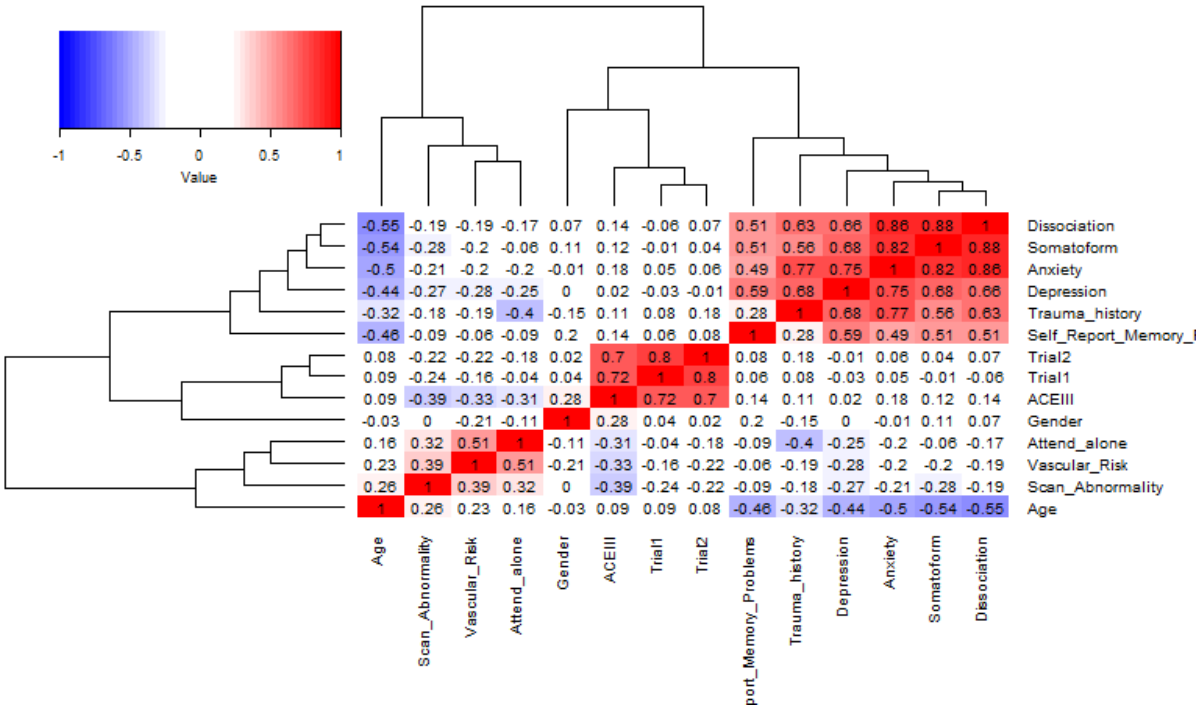
As can be seen from the table above, the addition of participant characteristics resulted in more accurate prediction of diagnostic category (X^2=17.53, $p < 0.001$) than would have been expected from the base rates for the condition alone. The addition of cognitive characteristics further enhanced the predictive accuracy of the model ($X^2 = 11.30$, $p = 0.004$). The neurological factors did not significantly improve the predictive accuracy of the model. However, the addition of psychological factors was associated with a significant increase in

the accuracy of the prediction of diagnostic category (X^2 = 11.584, p = 0.041). Finally, the addition of information regarding effort and engagement was not associated with an increase in predictive accuracy.

Correlations between predictor variables

Although the presence of collinearity between predictor variables has little impact on the overall accuracy of the predictive model, the presence of marked collinearity between predictor variables can confound the estimation of the unique contribution of each of the individual predictor variables to the overall prediction of diagnostic category. Figure 3 presents the correlation matrix between the predictor variables used in the logistic regression analysis.

Figure 3: Heat map of the correlation matrix between predictor variables



As can be seen from figure 3 there is marked positive correlations between the psychological factors and the neurological factors, showing a negative correlation with age. Therefore, a forward stepwise procedure was introduced for the block containing the psychological factors and the logistic regression was recalculated.

The goodness-of-fit chi-square was calculated at the addition of each of the blocks to the predictive model. The goodness of fit associated with the addition of each of the blocks and for all variables within the model is presented in the table below.

Table 4: Goodness of fit Chi-square for block and model for hierarchical logistic regression

	Variables added to the model	**Block Chi-square (p)**	**Model Chi-square (p)**
Block 1	Age, Gender and Attended alone	17.527 (<0.001)	17.527 (<0.001)
Block 2	Self-reported memory difficulties, ACEIII	11.299 (0.004)	28.826 (<.0.001)
Block 3	Scanning Abnormality identified, Vascular risk	1.046 (0.593)	29.871 (<.001)
Block 4	Depression	11.584 (<.001)	41.455 (<.001)
Block 5	Trial 1 TOMM, Trial 2 TOMM	0.000 (0.999)	41.455 (<.001)

As can be seen from the table above, the addition of participant characteristics resulted in more accurate prediction of diagnostic category (X^2=17.53, $p < 0.001$) than would have been expected from the base rates for the condition alone. The addition of cognitive characteristics further enhanced the predictive accuracy of the model ($X^2 = 11.30$, $p = 0.004$). The neurological factors did not significantly improve the predictive accuracy of the model. The forward stepwise addition of psychological factors resulted in only depression being added to the predictive model. Overall, psychological factors were associated with a significant increase in the accuracy of the prediction of diagnostic category ($X^2 = 11.584$, $p = 0.041$). Finally, the addition of information regarding effort and engagement was not associated with an increase in predictive accuracy. Therefore, the model suggested by the hierarchical logistic regression analysis included:

Block 1: Participant Characteristics = Age, Gender and Attended alone
Block 2: Cognitive Characteristics = Self-reported memory difficulties, ACE-III
Block 4: Psychological Factors = Depression

Finally, the participant characteristics, cognitive characteristics and depression score was entered into a forward stepwise logistic regression in order to identify the minimum model for the prediction of diagnostic category. At step 1 ACE-III scores were entered into the model ($X^2 = 14.35$, $p < 0.001$) and at step two depression scores were added to the model ($X^2 = 41.46$, $p < 0.001$).

Table 5: Minimum model from forward stepwise logistic regression

	Variables added to the model	Block Chi-square (p)	Model Chi-square (p)
Step 1	ACE-III	14.354 <0.001	14.354 <0.001
Step 2	Depression	41.455 <0.001	41.455 <0.001

The model *log(p/1-p) = -1629.860 + (17.941937*ACEIII) + (33.388*Depression) + error* using a cut-off of *log(p/1-p)* > 0.5 as indicative of FMD, with ACE-III and depression as predictor variables resulted in perfect separation of the Dementia and FMD patients (see table 6), with higher values of ACE-III and depression being associated with FMD.

Table 6: Classification table

		Predicted		
		Dementia	**FMD**	**Percentage Correct**
Observed	Dementia	14	0	100.0
	FMD	0	16	100.0
Overall Percentage				100.0

Complete separation occurs whenever the linear function of predictors can generate perfect predictions of the dependent variable and is most likely in small samples in which the complete separation reflects a failure to capture the true variance in the predictor variables. Complete separation may result in inflated or (near) infinite parameter estimates (Heinze & Schemper, 2002) and can result in the overestimation of sensitivity specificity and area under the receiver operating characteristic curve. Therefore, the odds ratios estimates for the ACE-III and depression were recalculated using the exact logistic regression procedure described by Heinze & Schemper (2002).

Table 7: Exact logistic regression parameter estimates

	Odds ratio	Prob.	[95% conf.interval]	
ACE-III	1.216287	0.0000498	1.103134	+inf
Depression	1.400859	0.0003516	1.172028	+inf

The inclusion of the ACE-III resulted in a 21.63% increase in diagnostic accuracy and the inclusion of depression was associated with a 40.1% increase in diagnostic accuracy.

The differentiation of MCI and FMD

A hierarchical logistic regression was undertaken in order to identify factors that distinguish between a diagnosis of MCI and FMD. The regression included 26 participants. The predictor variables were entered in five blocks as indicated in the previous analysis.

The goodness-of-fit chi-square was calculated at the addition of each of the blocks to the predictive model. The goodness of fit associated with the addition of each of the blocks and for all variables within the model is presented in the table below:

Table 8: Goodness of fit chi-square for the hierarchical logistic regression

	Variables added to the model	Block Chi-square (p)	Model Chi-square (p)
Block 1	Age, Gender and Attended alone	16.346 (<.001)	16.346 (<.001)
Block 2	Self-reported memory difficulties, ACE-III	1.236 (0.539)	17.582 (0.004)
Block 3	Scanning Abnormality identified, Vascular risk	3.488 (0.175)	21.070 (0.004)
Block 4	History of psychological trauma, Depression, Anxiety, Dissociation, Somatoform,	9.483 **(0.**091**)**	30.553 (0.002)
Block 5	Trial 1 TOMM, Trial 2 TOMM	0.00 (0.999)	30.553 (0.006)

As can be seen from the table above, the addition of participant characteristics resulted in more accurate prediction of diagnostic category (X^2=16.35, $p < 0.001$) than would have been expected from the base rates alone. The addition of cognitive characteristics ($X^2 = 1.24$, $p = 0.5.34$) and neurological factors ($X^2 = 3.488$, $p = 0.175$) did not significantly enhanced the predictive accuracy of the model. However, complete separation of MCI and FMD patients was achieved with the inclusion of the psychological factors which evidenced a trend to statistical significance ($X^2 = 9.43$, $p = 0.091$).

As can be seen from collinearity heat map shown previously in figure 3, there is marked positive correlations between the psychological factors and the neurological factors, showing a negative correlation with age. Therefore, a forward stepwise procedure was introduced for the block containing the psychological factors and the logistic regression was recalculated.

The goodness-of-fit chi-square was calculated at the addition of each of the blocks to the predictive model. The goodness of fit associated with the addition of each of the blocks and for all variables within the model is presented in the table below:

Table 9: Goodness of fit chi-square for the hierarchical logistic regression with forward stepwise selection for block 4

	Variables added to the model	Block Chi-square (p)	Model Chi-square (p)
Block 1	Age, Gender and Attended alone	16.346 (<.001)	16.346 (<.001)
Block 2	Self-reported memory difficulties, ACE-III	1.236 (0.539)	17.582 (0.004)
Block 3	Scanning Abnormality identified, Vascular risk	3.488 (0.175)	21.070 (0.004)
Block 4	Depression	9.483 **(0.**091**)**	30.553 (0.002)
Block 5	Trial 1 TOMM, Trial 2 TOMM	0.00 (0.999)	30.553 (0.006)

Therefore, the model suggested by the hierarchical logistic regression analysis included:

Block 1: Participant Characteristics = Age, Gender and Attended alone
Block 4: Psychological Factors = Depression

Finally, the participant characteristics, and Depression scores were entered into a forward stepwise logistic regression in order to identify the minimum model for the prediction of diagnostic category.

Table 10: Minimum model from forward stepwise logistic regression

	Variables added to the model	Block Chi-square (p)	Model Chi-square (p)
Step 1	Depression	14.576 (<0.001)	14.576 <0.001
Step 2	Attend alone	7.644 (0.006)	22,219 (<0.001)

Using the model *log(p/1-p) = 18.635 + (0.535*Depression) + (-21.958*Attended Alone) + error* and using a cut-off of *log(p/1-p)* > 0.5 as indicative of FMD, achieved an overall accuracy of 96.2%, with higher values of depression and attending alone being associated with FMD.

Table 11: Classification table

		Predicted		
		MCI	**FMD**	**Percentage Correct**
Observed	MCI	8	0	100.0
	FMD	1	17	100.0
Overall Percentage				100.0

The odds ratios estimates for depression and attending alone were recalculated using the exact logistic regression procedure described by Heinze & Schemper (2002).

Table 12: Exact logistic regression parameter estimates

	Odds ratio	**Prob.**	**[95% conf.**	**interval]**
Attended alone	0.149426	.0568182	0	1.07476
Depression	1.535159	.0002057	1.167275	2.586759

The inclusion of depression was associated with a 14.9% increase in diagnostic accuracy and the observation of whether the patient attended alone was associated with an 85% increasing diagnostic accuracy.

DISCUSSION

The current study aimed to understand what factors are most useful in discriminating between functional and non-functional diagnoses. The study was most interested in exploring factors that are not routinely collected as part of an initial memory assessment. 42 participants took part in the study, 16 with a diagnosis of Dementia, 18 with a diagnosis of FMD and 8 with a diagnosis of MCI.

Participant characteristics

Participant characteristics are collected as part of a standard memory assessment and include factors such as gender, age and whether or not someone attended alone or with a family member. Although reviews of memory services have suggested that younger age (London Clinical Networks, 2020) and attending alone (Stone et al, 2015; Bailey et al, 2018; London Clinical Networks, 2020) appear to be more common in diagnosis of FMD, no known study to date has explored this statistically. Overall, it was found that the inclusion of participant characteristics resulted in a more accurate prediction of diagnosis than would have been expected from base rates for the condition alone.

When looking at the individual predictive factors, the current study found evidence to suggest that age was significantly different between the diagnostic groups with FMD having a mean average age 10 years younger (63 years old) than those diagnosed with MCI and Dementia. This fits with Stone and colleagues (2015) and London Clinical Networks (2020) observations of memory clinics, with both stating that clients with FMD tend to be under the age of 65. The statistical difference between FMD and the other two diagnostic groups, found in the current study, adds value to observations noted in reviews. The current study provides some provisional evidence that age has potential as a phenotype of FMD.

The current study also found statistical evidence to suggest that patients diagnosed with FMD were more likely to attend their appointment alone. This finding supports the observations in reviews by London Clinical Networks (2020), Stone et al (2015) and Bailey et al (2018) which all suggested that attendance alone appeared to be more prevalent. In the current study, half of the participants diagnosed with FMD attended their appointment alone. This is a stark difference to those diagnosed with Dementia (with only one person attending alone) and

those diagnosed with MCI with all patients being accompanied. When predicting the diagnosis between FMD and MCI, observation of whether the patient attended alone was associated with an 85% increasing diagnostic accuracy. Although these findings need to be treated with caution due to sample size, with the MCI diagnostic group being particularly small (N = 8), there is preliminary evidence that attending alone might be an effective way of discriminating between FMD and MCI. This is a particularly important finding when taking into account the rates of misdiagnosis between the two diagnostic groups as suggested by previous reviews (Stone et al, 2015).

Cognitive Characteristics

Cognitive characteristics are also routinely collected as part of a standard memory assessment. Thus often includes use of the ACE-III and an interview that considers self-reported memory problems. Overall, cognitive factors helped to enhance the predictive accuracy for the model of Dementia vs FMD but did not further increase the predictive value of the model for MCI vs FMD.

Using chi-square tests, the question from the GDS ("Do you feel that you have more problems with memory than most?") illustrated that there were significant differences between diagnoses in the self-report of memory problems. For example, patients diagnosed with dementia were more likely to answer no and patients diagnosed with FMD and MCI were more likely to say yes. This question appears useful for differentiating between a Dementia and FMD but much less useful for differentiating between FMD and MCI. This finding highlights the difficulties with insight in Dementia (Green et al, 1993; Reed, Jagust & Coulter, 1993; Lopez et al, 1994; Kotler-Cope & Camp, 1995; Vasterling et al, 1995; Ott et al, 1996; Ott, Noto & Fogel, 1996) and health anxiety that is often found in MCI populations (Chen, Hu, Jiang & Zhou, 2018). It is also important to comment that the variations in self-reported cognitive problems support a wide assessment that considers more than just the patient's voice which does not appear to match cognitive difficulties in testing.

The ACE-III is used as a screening tool for dementia, with a cut off score of 82 and below indicating a potential dementia. In regard to differences between the diagnoses, the current study found patients with dementia had significantly lower ACE-III scores (mean=64, sd=15.72) in comparison to MCI (mean = 82.81, sd=15.78) and FMD (mean = 82.82,

sd=9.51). The current study suggests caution is needed when interpreting the ACE-III. Mean scores for those with FMD and MCI just meet the cut-off criteria for a possible Dementia and therefore these patients would likely be offered further assessment. As stated in the introduction, further assessment for those with FMD is timely, costly, and does not necessarily clarify diagnosis. Additionally, standard deviations in each of the diagnostic groups was large, suggesting large variations in scores and cross over between the diagnostic groups. When trying to predict the diagnosis between MCI and FMD, the ACE-III and other cognitive characteristics did not significantly enhance the predictive accuracy of the model. We can perhaps, however, be confident that lower scores on the ACE-III far below the cut-off indicate a Dementia and are less indicative of FMD or MCI. In fact, the inclusion of the ACE-III in the exact logistic regression resulted in a 21.63% increase in diagnostic accuracy between Dementia and FMD.

The current study provides some preliminary evidence that the ACE-III is an important part of the diagnostic process, helping to identify those with a well-established Dementia but should be used with caution when considering those patients near to the cut-off score. Scores in this area could indicate multiple diagnoses and may result in misdiagnosis between FMD and MCI, who perform similarly. The ACE-III may also lead to memory nurses referring those with FMD for further testing with a neuropsychologist. This finding supports Beishon et al, (2019) review which suggested that lower thresholds of the ACE-III have better specificity and that the screening tool should be used with caution as part of a full assessment. The current study highlights the need for further research into the ACE-III and its specificity and sensitivity of thresholds in regards to differential diagnoses.

Neurological factors

Neurological factors include vascular risk factors, which are routinely collected as part of an initial assessment, and brain scanning, which is not necessarily a part of every patient's memory assessment. In fact, 10 of the 42 patients did not have a brain scan. The type of brain scan also varies, with six clients having more than one brain scan. Brain scans are used routinely to help diagnose the type of Dementia but were not shown in this study to have any significant group difference between the diagnostic categories. It appears that patients with FMD and MCI were just as likely to be offered a brain scan. In addition, the extra information collected from a brain scan and medical notes (vascular risks) did not

significantly enhance the predictive accuracy of the model for Dementia vs FMD or MCI vs FMD. This finding supports the motivation to reduce brain scanning except in cases where a Dementia is well established and guidance is needed on a differential diagnosis. Brain scanning is costly and timely and does not appear to enhance the ability to offer guidance on differentiating between functional and non-functional memory problems.

In regard to individual predictive factors, vascular risk factors were significantly different in the FMD group in comparison to MCI and Dementia. According to the heat map, there were positive correlations between the predictor variables vascular risks and age. There is much evidence to suggest that vascular risk factors are a normal part of the aging process, with older adults having more vascular risks (Rogers et al, 2019). It is likely, therefore, that the significant differences found between the FMD group and non-functional memory groups (Dementia and MCI) are based on their younger age. This is further evidenced by vascular risk factors not significantly enhancing the predictive accuracy over and above personal characteristics which included age. Although vascular risk factors may help to differentiate between types of Dementia, it appears that they do not hold much value in discriminating between FMD and non-functional diagnoses.

Effort and engagement

Effort and engagement factors included the mean scores on TOMM trial 1 and 2 and the failing rate on Trial 2. It was predicted that effort and engagement may help to identify those with FMD as studies have suggested that those with FMD may intentionally or non-intentionally exhibit excessive cognitive symptoms, having poor performance in measures of effort (Dellis & Wetter, 2007). In comparison, effort testing has been shown to be relatively preserved for those with Dementia (McGuire, Crawford & Evans, 2019) especially in cases where Dementia is not severe (Walter et al, 2014). Contrary to hypotheses, the current study found that effort and engagement factors did not significantly enhance the predictive accuracy of the model for Dementia vs FMD or MCI vs FMD.

In regard to individual predictive factors, the participants who failed TOMM trial 2 significantly differed between the diagnostic categories. The Dementia diagnosis group had the highest rate of failure whereas no one failed in the MCI group and only two participants failed in the FMD group. The TOMM therefore did have some ability to differentiate

between the groups but not in the way one would have expected and not strongly enough to enhance predictive accuracy of the model. The current study found the opposite effect to what was expected, suggesting the use of the TOMM is not accurate for identifying those with FMD. Furthermore, despite the majority of participants in the Dementia group having "mild" dementia (mean ACE-III score = 64), with a cut-off score of 61 points in the ACE-III being sensitive to indication of moderate dementia (Giebel & Challis, 2017), this study suggests that the TOMM is not fit for purpose for those with cognitive difficulties even in their mild stages. Previous research has suggested adjusting the cut-off to 50% correct in order to keep sensitivity on the TOMM. In the current study this adjustment would have resulted in not one person from any of the diagnostic categories failing the TOMM. Again, this indicates that the TOMM is not a good tool for helping to differentiate between diagnoses and was not successful in identifying patients with FMD.

Psychological factors

Psychological factors are not routinely collected as part of a memory assessment. Literature around FMD suggests that psychometrics and psychological trauma history may be a way to help differentiate between FMD and non-functional diagnoses (Reid & Maclullich, 2006; Hill et al, 2006; McWhirter et al, 2019). Overall, the current study found evidence to suggest that psychological factors were associated with a significant increase in the accuracy of the prediction of diagnostic category between FMD and Dementia. Additionally, when differentiating between FMD and MCI, the inclusion of psychological factors achieved complete separation, evidencing a trend to statistical significance.

When looking at the individual predictor factors, there were significant group differences in experiences of psychological trauma. Most patients diagnosed with FMD had experiences of psychological trauma in comparison to none of the MCI patients and very few of the patients diagnosed with Dementia. This finding fits with literature which suggests that FMD tends to be associated with mental health factors such as depression and anxiety (McWhirter er at, 2019) and the widely accepted relationship between mental health and experiences of psychological trauma (Kessler, 2010; Mauritz, 2013; Khalifeh, 2015). The current research provides preliminary support for initial memory assessments to consider experiences of psychological trauma.

Mean depression (GDS), anxiety (GAS) and dissociation scores (DES-II and SDS) also showed significant differences between the diagnostic groups with FMD having higher mean scores in all. Participants with FMD appeared to be more depressed, anxious and had higher rates of dissociation. The mean scores indicated "Moderate" depression (mean=10.22, sd=4.41), "Severe" anxiety (mean = 14.28, sd = 4.41), high levels of somatoform dissociation (34,72, sd=9.99) and approaching high levels of dissociation (mean 27.65, sd=16.5). Standard deviations were fairly low on the depression and anxiety scales and larger for the dissociation measures, particularly the DES-II. This might be reflective of the number of questions, with the dissociation measures being much larger. It may also be indicative that dissociation is a much larger construct, the measure showing sensitivity but not specificity. Brown (2006) proposed a continuum view of dissociation with different mechanisms dependant on conditions and severity. Given the DES-II and SDS are for assessing severe dissociative disorder, it might be that scales looking for milder more common forms of dissociation might be more helpful in this regard.

When considering correlations between the predictor variables, marked collinearity was found between the psychological factors. A goodness of fit chi square identified depression (mean GDS score) as the most powerful predictor variable. This suggests that the other psychometric measures are perhaps sensitive but not specific and do not detect much above and beyond depression in association with FMD. Depression was associated with a 40.1% increase in diagnostic accuracy between FMD and Dementia and a 14.9% increase in accuracy between FMD and MCI. Those diagnosed with FMD were more likely to have pathological scores on the GDS. This provides preliminary evidence to suggest that the GDS is an effective measure in discriminating between FMD and non-functional diagnoses and would be a useful tool to include in early assessments of memory. This finding is in keeping with McWhirter et al's, 2019 review which suggested that many studies have evidenced a FMD phenotype of which depression symptoms were the most common. A study by Matternich, Schmitdtke and Hull (2009) also evidenced elevated depression scores in FMD in comparison to the general population which are pathological.

It is interesting to consider why depression, above and beyond dissociation, anxiety and history of trauma has such powerful discriminant validity and presence in FMD. There is vast evidence to suggest that people experiencing major depression report cognitive disorder with deficits in various domains expanding from attention to executive functioning, memory and

processing speed (McIntyre et al, 2015; Millan et al, 2012). Evidence suggests that cognitive complaints often persist past remission of depressive symptoms. Prevalence rates of cognitive complaints range from 85-94% of the time during a depressive episode and 39-44% of the time during remission (Conradi, Ormel & de Jonge, 2011). The DSM-V (American Psychiatric Association, 2013) identifies cognitive problems as a core symptom of depression within the diagnostic criteria for major depression disorder. It is clear that the diagnostic criteria for depression and for FMD overlap considerably. Depression has also been shown in some studies to overlap with trait anxiety and dissociation. A meta-analysis (Knowles & Olatunji, 2020) has suggested that depression has a significantly higher trait anxiety than those with anxiety disorder, concluding that trait anxiety and depression are closely related. High trait anxiety has also been shown to correlate with cognitive difficulties including reduced neural processing efficiency (Basten, Stelzel & Fiebach, 2011; Sylvester et al, 2012). In addition, a study by Lipsanen, Saarikarvi & Lauerman (2004) suggested that although somatization, dissociation and depression are distinct constructs, they correlate considerably with overlapping parts of the construct relating to distress. The overlapping constructs may explain why dissociation and anxiety measures were predictive but not over and above depression.

Future research and limitations

There are limitations to this study, mainly the sample size. Unfortunately, COVID-19 has impacted on the memory services greatly, increasing the amount of time for diagnosis due to delays in brain scans. Although several more participants agreed to take part in the study, brain scans were not conducted in time for them to have their diagnosis confirmed and be included within analysis. Additionally, due to the vulnerability of older people, recruitment for research was more difficult as national guidelines at the time of recruitment indicated that contact with others should be limited. National lockdowns also halted recruitment numerous times. The impact of a smaller sample size is that the data from the current study is perhaps not generalisable to the population as it is likely to only be fitting of the current sample. This is partially because of the large number of predictor variables used within analysis. Further research with different and larger samples is therefore needed to support the findings and ensure generalisability.

A standard memory assessment which collects information on age and uses the ACE-III as a screening tool has useful information for differentiating between diagnoses. The current study provides evidence to suggest that one can have confidence that younger patients are more likely to have FMD and those with lower ACE-III scores, far below cut-off, are more likely to have a Dementia. Although the ACE-III appears to be a good tool in identifying those with a possible Dementia, it is less effective at differentiating between MCI and FMD who were found to have similar mean scores around the ACE-III cut-off. Therefore, it is essential that further methods are developed within initial assessments in order to avoid misdiagnosis and add confidence to the diagnostic process. Age might be a factor that experienced clinicians use implicitly as part of their diagnostic decision making. The current study suggests that clinicians can use this information more explicitly.

Attendance alone or accompanied is usually documented in the assessment process in regard to accurate note taking rather than for diagnostic value. Reviews have noted that patients with FMD are more likely to attend alone and the current study found evidence to suggest that attendance alone greatly improved the diagnostic accuracy between FMD and MCI. There is some evidence to suggest therefore that accompanied or unaccompanied attendance is documented within assessment as it can be utilised as a predictor variable to help inform diagnostic decisions.

Above and beyond all of these factors, depression scores increase the diagnostic accuracy between both FMD and Dementia and FMD and MCI. This provides rationale for including the GDS in assessments for memory. The findings of the current study clearly show the potential predictive validity of many measures including ACE-III, GAD, GDS, DES-II and SDS. Further research, however, is needed to understand what parts of each measure are relevant and predictive. As stated previously, the dissociation measures are vast and there is a possibility of some aspects of the measure being more predictive than other aspects of dissociation. There is potential utility of item analysis to explore the individual items of the psychometrics. This may allow for the creation of a shorter screening measure that amalgamates the most predictive items from measures.

The current study suggests that it may be possible to create a phenotype of FMD which includes attendance alone, younger age, borderline or above cut-off ACE-III scores and high depression scores. This phenotype is suspected to have good diagnostic accuracy and may

help to identify and diagnose patients with FMD earlier in the memory assessment process so that brain scans and neuropsychology referrals are not required. Future research could examine the validity of a screening tool which uses these factors to assist those referring for memory assessments such as General Practitioners. This would help with diagnostic differentiation earlier in the process so that only those with suspected non-functional memory complaints are referred to the memory service. Patients with FMD would gain faster access to mental health support and the waiting times for assessment and diagnosis to be reduced for those with MCI and Dementia. In some cases there are likely to be significant comorbidities whereby in depth neuropsychological testing is needed. However, the above factors will help the differentiation process within initial assessment so that timeliness is improved in addition to rates of referral. This will allow neuropsychologists to only see the more complex cases, reducing their waiting lists to contribute to shorter times for diagnosis.

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LITERATURE REVIEW PRESS RELEASE

The Dissociation Experiences Scale (DES): the most commonly used measure of dissociation in practice and research found to be reliable with an alpha coefficient that is accurate and stable over time, geography and language!

The DES and its updated version, the DES-II, are the most commonly used measure of dissociation in practice and research. Dissociation can be described as the action of disconnecting from yourself and the world around you (American Psychiatric Association, 2013). Dissociation can happen occasionally as a part of normal functioning but also can be related to a wide range of psychiatric disorders where it is more frequent and distressing (O'Neil & Dell, 2009; Sar et al, 2007). There is growing evidence that dissociation is a consequence of trauma (Carlson, Dalenberg & McDadeMontez, 2012; Gershuny & Thayer, 1999; Carrion & Steiner, 2000) and consequently dissociation is a concept that is central to psychology. Its relationship with adversity in childhood highlights a neglected public health problem.

Prevalence rates of dissociation are difficult to determine, however, a study by Sar (2011) suggests a general prevalence of 10% across clinical populations and the community. Given its prevalence across general and clinical populations, it is imperative that the tool used to measure the construct is reliable so that results can be interpreted with confidence.

Researchers at the University of Birmingham found that no up to date meta-analysis on reliability exists, with the last meta-analysis conducted in 1996. Therefore, the Birmingham team assessed the internal reliability of the DES and DES-II using a meta-analysis to provide an accurate estimate using statistical methods. A systematic review of the literature provided 144 studies with 47,791 participants that had used the DES or DES-II and reported on its internal reliability. The results of this review demonstrated a "good" weighted alpha value of 0.93 which is far above the commonly acceptable minimum value of 0.7. Furthermore, the alpha coefficient of 0.93 has remained consistent between van Ijzendoorn and Schuengel's (1996) meta-analysis and the current meta-analysis despite the addition of 128 studies from across the globe. The newly added studies included different language variants and the more recently updated DES-II. It is suggested, therefore, that the alpha coefficient of the DES is accurate and stable.

For more information, please contact Chloe Herrick-Bourke, School of Psychology, University of Birmingham, [redacted]

Note to editors: The University of Birmingham is ranked amongst the world's top 100 institutions.

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EMPIRICAL PAPER PRESS RELEASE

Potential to save the memory services in the NHS thousands: A phenotype has been discovered to help with the differentiation between Functional Memory Disorder and Dementia

It is estimated that there are 900,000 people in the UK living with dementia (Alzheimer Research UK, 2019). Dementia is characterised by acquired losses of cognitive ability and emotional ability which interfere with quality of life and daily functioning (Geldmacher & Whitehouse, 1996). The Prime Minister's 2020 Challenge on Dementia aims for dementia services to be diagnosing dementia within six weeks from a general practitioner (GP) referral (Department of Health and Social Care, 2015). In March 2020, an audit was published which explored the performance of memory services in five regions of NHS England (Dementia Clinical Network, 2020). Overall, only 26% of patients were diagnosed within the six weeks of referral, with an average waiting time of 5 weeks for a brain scan alone (Dementia Clinical Network, 2020). The audit concludes that memory services need to consider how they can streamline services in order to work towards timely diagnosis.

There are many barriers to a timely diagnosis. One of those barriers is ensuring accurate diagnosis between Functional Memory Disorder (FMD), Mild Cognitive Impairment (MCI) and Dementia, which can present similarly in memory assessments. As they present similarly, there are high rates of misdiagnosis and referrals for further examinations such as brain scans and neuropsychology assessments. The diagnoses are distinctively different, and each require a different treatment pathway. Dementia is a progressive illness whereas MCI and FMD are not. FMD are usually related to combination of factors that impact on concentration and attentional ability, including mental health difficulties and pain. MCI on the other hand, is characterised by objective cognitive impairment but not to the extent of dementia and without progression or impact on daily living skills (NHS, 2014). If one can find more reliable and efficient ways to differentiate between diagnoses, then this could help reduce waiting times by reducing the number of people that need a thorough memory assessment.

Researchers at the University of Birmingham sought to investigate the predictive validity of psychometrics and an effort and engagement measure in differentiating between Dementia, FMD and MCI. A hierarchal linear regression was conducted to explore predictive factors of diagnosis. Researchers found that predictive factors of age, attending alone, a commonly used screening measure (ACE-III) and depression all hold discriminant value between diagnoses.

In particular, patients with FMD are younger than Dementia and MCI patients, have higher ACE-III scores than those with Dementia and are more likely to attend alone than the other diagnoses.

Researchers found preliminary evidence to support a phenotype of FMD which could be used to help create a screening measure in order to diagnose more effectively in terms of time and accuracy. By developing a screening measures, General Practitioners could reduce the number of patients referred to memory clinics sending only those with suspected Dementia and MCI. This would help ensure everyone has a timely diagnosis and quick access to the treatment they require.

For more information, please contact Chloe Herrick-Bourke, School of Psychology, University of Birmingham,

Note to editors: The University of Birmingham is ranked amongst the world's top 100 institutions.

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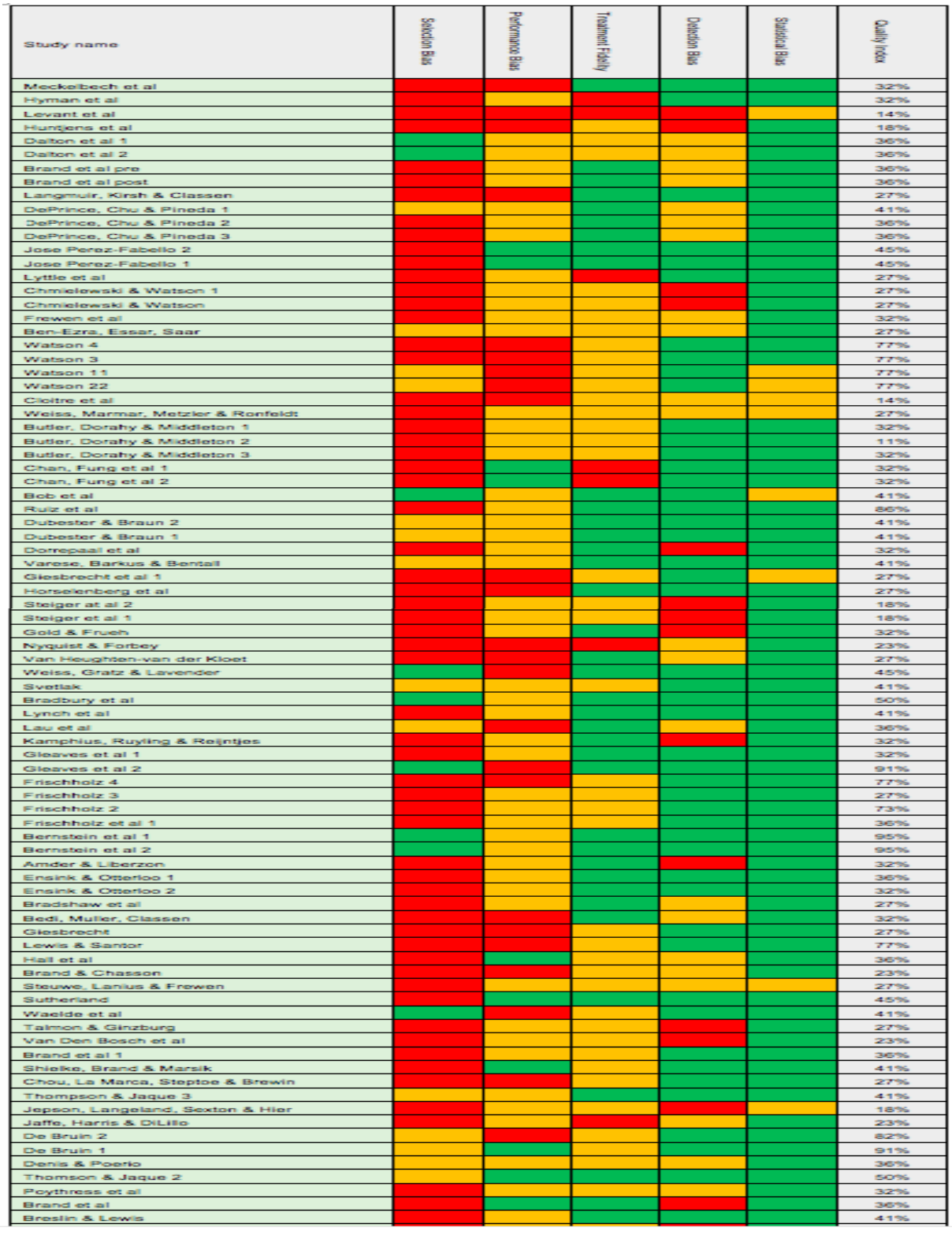
APPENDICES

Appendix 1: Summary of applied quality criteria

(green indicates low risk of bias; amber indicates unclear risk of bias and red indicates high risk of bias)



Study name	Selection Bias	Performance Bias	Treatment Fidelity	Detection Bias	Statistical Bias	Quality Index
Meckelbech et al						32%
Hyman et al						32%
Levant et al						14%
Huntjens et al						18%
Dalton et al 1						36%
Dalton et al 2						36%
Brand et al pre						36%
Brand et al post						36%
Langmuir, Kirsh & Classen						27%
DePrince, Chu & Pineda 1						41%
DePrince, Chu & Pineda 2						36%
DePrince, Chu & Pineda 3						36%
Jose Perez-Fabello 2						45%
Jose Perez-Fabello 1						45%
Lyttle et al						27%
Chmielewski & Watson 1						27%
Chmielewski & Watson						27%
Frewen et al						32%
Ben-Ezra, Essar, Saar						27%
Watson 4						77%
Watson 3						77%
Watson 11						77%
Watson 22						77%
Cloitre et al						14%
Weiss, Marmar, Metzler & Ronfeldt						27%
Butler, Dorahy & Middleton 1						32%
Butler, Dorahy & Middleton 2						11%
Butler, Dorahy & Middleton 3						32%
Chan, Fung et al 1						32%
Chan, Fung et al 2						32%
Bob et al						41%
Ruiz et al						86%
Dubester & Braun 2						41%
Dubester & Braun 1						41%
Dorrepaal et al						32%
Varese, Barkus & Bentall						41%
Giesbrecht et al 1						27%
Horselenberg et al						27%
Steiger et al 2						18%
Steiger et al 1						18%
Gold & Frueh						32%
Nyquist & Forbey						23%
Van Heughten-van der Kloet						27%
Weiss, Gratz & Lavender						45%
Svetlak						41%
Bradbury et al						50%
Lynch et al						41%
Lau et al						36%
Kamphius, Ruyling & Reijntjes						32%
Gleaves et al 1						32%
Gleaves et al 2						91%
Frischholz 4						77%
Frischholz 3						27%
Frischholz 2						73%
Frischholz et al 1						36%
Bernstein et al 1						95%
Bernstein et al 2						95%
Amder & Liberzon						32%
Ensink & Otterloo 1						36%
Ensink & Otterloo 2						32%
Bradshaw et al						27%
Bedi, Muller, Classen						32%
Giesbrecht						27%
Lewis & Santor						77%
Hall et al						36%
Brand & Chasson						23%
Steuwe, Lanius & Frewen						27%
Sutherland						45%
Waelde et al						41%
Talmon & Ginzburg						27%
Van Den Bosch et al						23%
Brand et al 1						36%
Shielke, Brand & Marsik						41%
Chou, La Marca, Steptoe & Brewin						27%
Thompson & Jaque 3						41%
Jepson, Langeland, Sexton & Hier						18%
Jaffe, Harris & DiLillo						23%
De Bruin 2						82%
De Bruin 1						91%
Denis & Poerio						36%
Thomson & Jaque 2						50%
Poythress et al						32%
Brand et al						36%
Breslin & Lewis						41%

Study name	Selection Bias	Performance Bias	Treatment Fidelity	Detection Bias	Statistical Bias	Quality Index
Bertolon & Raffard						27%
Watson 1						36%
Watson 2						36%
Merckelbach et al						27%
Merckelbach, Muris, Horselenberg & Stougie						36%
Alderson-Day et al						32%
Kwapil 2						32%
Kwapil 1						32%
Sutin & Stockdale						32%
Bruce, Ray & Carlson						86%
Bruce et al 2						36%
Rosik & Soria						55%
Modestin, Hermann & Endrass						45%
Monier et al						27%
Classen et al						36%
De Beradis et al						45%
Berry, Flemming, Wong & Bucci						36%
Van der Boom et al						41%
Lahav et al						41%
Wright & Loftus						45%
Rassin & Van Rootselaar						32%
Stockdale et al						86%
Thomson & Jaque						45%
Skrzypinska						27%
Cardena & Marcusson-Clavertz						41%
Cardena et al						32%
van der Kloet et al						41%
Yu						45%
Schuengal et al						27%
Sar et al						91%
Ram-Vlasov						36%
Perez Fabello & Campos						95%
Scimeca et al						41%
Oh, Kim & Kim						50%
Bizik et al						36%
Gutierrez Wang et al						95%
van Emmerik et al						45%
Ginzberg et al						36%
Maaranen et al						50%
Favaro et al						32%
Ullah et al						45%
Jopp et al 3						73%
van der Heide et al						23%
Burg et al						32%
Kroger et al						86%
Lewis-Fernandez						32%
Bob et al 2						36%
Soffer-Dudek & Shahar 1						32%
Soffer-Dudek & Shahar 2						32%
Polemikou & Vantarakis						45%
Schimmenti						100%
Bob et al 3						32%
Cracco et al						32%
Evren et al						36%
Zoroglu et al						36%
Favaro et al						23%
Darves-Bornoz						73%
Zerach et al						27%
Kociman et al						45%
Lipsanen et al						95%
Zerach et al 2						32%
Ghaffarinejad						91%
Kotan et al						36%
Ko, Roh & Lee						41%
Schroeder						45%
Craparo et al						45%
Serrano-Sevillano						36%
Evren et al 1						36%
Gonzalez-Vazquez et al						27%
Dehghanizadeh et al						41%
Rosa Pena-Falcon et al						41%
Hagenaars et al						36%
Schimmenti						95%
Maaranen et al 1						45%
Carleton, Abrams & Asmundson						32%
Schimmenti et al						50%
Scheffers et al						27%
Shafer et al						41%
Schaefer et al						45%
Schaefer et al 1						32%
Sanders						36%
Putnam, Chu & Dill						41%
Bernstein & Putnam						41%
Draijer & Boon						36%
Donald, Fischer & Elnitsky						82%

Appendix 2: Ethics Confirmation

Health Research Authority

Mrs Chloe Herrick-Bourke
Trainee Clinical Psychologist
Birmingham & Solihull Mental Health Foundation Trust B1 Trust Headquarters
50 Summer Hill Road
Birmingham
B1 3RB

11 May 2020
Dear Mrs Herrick-Bourke

Study title:

REC reference: Protocol number: IRAS project ID:

Do dissociative screens have predictive and discriminate validity for differential diagnoses of dementia and functional memory disorder? 20/SW/0070

273569
273569

South West - Cornwall & Plymouth Research Ethics Committee

Thank you for your email on 7 May 2020. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 04 May 2020

Documents received

The documents received were as follows:

Approved documents

The final list of approved documentation for the study is therefore as follows:

Level 3 Block B Whitefriars Lewins Mead Bristol BS1 2NT

Telephone: 02071048071

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		01 August 2019
Participant consent form [Consent form]	2	07 May 2020
Participant information sheet (PIS) [Participant Information Sheet]	2	07 May 2020

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter]	0.1	19 March 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		01 August 2019
GP/consultant information sheets or letters [GP Letter]	1	18 June 2019
IRAS Application Form [IRAS_Form_25032020]		25 March 2020
IRAS Application Form XML file [IRAS_Form_25032020]		25 March 2020
IRAS Checklist XML [Checklist_25032020]		25 March 2020
Letter from sponsor [Sponsor letter]	0.1	19 March 2020
Other [Chris Jones CV]		
Participant consent form [Consent form]	2	07 May 2020
Participant information sheet (PIS) [Participant Information Sheet]	2	07 May 2020
Research protocol or project proposal [Research protocol]	0.1	25 November 2019
Summary CV for Chief Investigator (CI) [CV for CI]	1	18 June 2019
Validated questionnaire [DES]	1	18 June 2019
Validated questionnaire [SDQ]	1	18 June 2019
Validated questionnaire [GAS]	1	18 June 2019
Validated questionnaire [GDS]	1	18 June 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

Sharon Northey Approvals Manager

E-mail: [redacted]

20/SW/0070 Please quote this number on all correspondence

[redacted]

Copy to:

Joanne Sawyer , Black Country Partnership NHS Foundation Trust Lead Nation
approvals@hra.nhs.uk

Appendix 3: Information Sheet

Understanding the differences between dementia and memory problems that are not caused by dementia

Participant Information Sheet

We would like to invite you to take part in our research study which is being conducted as part of Chloe Herrick's Clinical Psychology Doctorate thesis and sponsored by the University of Birmingham. The research is being conducted under the School of Psychology with recruitment taking place across memory services in the Black Country Healthcare NHS Foundation Trust.

Please read this information carefully before deciding whether you wish to take part in the research study. If you would like any more information about the study or you have any health and / or language difficulties which make it difficult for you to read this information please contact the research team or you can ask someone to contact the research team on your behalf (see details at the end of the information sheet).

What is the purpose of the project?

The project aims to explore the differences between dementia and memory problems that are not caused by dementia. Currently, different types of memory problems are diagnosed through lengthy assessments which require specialist members of staff. There is a government strategy to ensure timely diagnosis of progressive memory problems like dementia. In order to assist with timely diagnosis, the study aims to understand more about the subtle differences between memory problems. It is hoped that understanding subtle differences will allow the creation of a screening tool which could be used to reduce the need for lengthy assessment, increasing chances of timely diagnosis.

Why have I been invited?

You have been invited to take part because you are an adult over the age of 50 years and have been referred to the memory services in the Black Country Healthcare NHS Trust for a memory assessment.

Do I have to take part?

No. Taking part in this project is entirely voluntary. You also have the right to withdraw from the project, and further details on this are listed below.

If I decide to take part in the research study, what will I be asked to do?

If you would like to participate in the research, you will be asked to sign a consent form. We will also ask your permission to access your clinical file which will provide details about your memory problems and the diagnosis. You will then be asked to complete two short questionnaires about your mood and two short questionnaires about unusual experiences which are sometimes related to specific types of memory problems. These questionnaire should take between 5 and 10 minutes each to complete. You will then be asked to complete a short test of your thinking which will take roughly 20 minutes.

Taking part in this study is estimated to take between 40/50 minutes although could last up to an hour if more support is needed. We will only need to meet with you once. We can meet at your local memory service, GP surgery (subject to approval), or within your own home. It will be conducted by Chloe Herrick (Clinical Psychologist in training, University of Birmingham) who is the named researcher on this project.

Your participation in this study is voluntary and you are free to withdraw at any time before data collection without giving a reason. Withdrawing from the study will not affect the care you receive.

What are the benefits of taking part?

We cannot promise that the project will have any direct benefit for you. However, we hope that the information that we get from this project will allow us to better understand the differences between different types of memory problems so that we can develop quicker ways to provide differential diagnosis.

What are the potential risks of taking part?

Although we do not anticipate participating in the study to be a distressing process, some of the topics covered by this project are sensitive and relate to your mental health, which you might find upsetting. If this does happen and you feel that you do not want to continue with participation in the research, you can withdraw at any time. We endeavour to ensure that support is available for if you find the content of questionnaires distressing. The research is conducted by a Trainee Clinical Psychologist and supervised by two Clinical Psychologists whose details are at the end of this information sheet. If the researcher is worried about you, or if you have concerns, a referral to specialist mental health services by writing to your GP will be considered. If you wish to discuss any concerns, please contact one of the researchers. In addition you will be provided with contact details of third party organisations that would also be able to offer support and guidance.

If I decide to participate, what will happen to the information I provide?

Personal identifying information, such as names, ages, addresses, telephone numbers and email addresses will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998 & 2018. Personal identifying information will be stored for the duration of the study on a password protected portable hard drive that is kept in a locked filing cabinet at Edward Street Hospital. Your completed questionnaires will be stored separately from the personal identifying information described above in a locked filing cabinet at Edward Street Hospital. Your name will not appear on the completed questionnaires. Instead, each participant will be allocated a participant number and this will appear on the questionnaires instead of names. An electronic file will be created which links the participant number to the participant name which will be stored on a password protected portable hard drive kept in a locked filing cabinet at the University of Birmingham. Only the research team have access to the research project filing cabinets. Anonymised data will be kept for 10 years and then destroyed.

In the unlikely event that the research team have concerns about the welfare of a participant, information will be disclosed as necessary.

If I would like to participate in the project, what should I do now?

Please remember that participation in the project is purely optional and the decision not to participate will not restrict access or affect the right to any health services. If you decide after reading this information sheet that you might be interested in taking part, please either contact the researcher using the details at the bottom of this information sheet, or let a member of the memory service know and they will pass on your contact details to the researcher who will contact you.

What if I change my mind about participating after I have provided consent?

Even after you have provided consent to participate in the study, you can request to be withdrawn from the study and for your research data to be destroyed without giving a reason. This will not restrict access or affect the right to any health services. You will have up to the point in which data is analysed (3 months after participating) to indicate that you would like to withdraw from the study. This is purely for practical reasons as after your personal identifying information has been destroyed, your personal details will no longer be linked to the information collected as part of this study. This means that we would no longer be able to trace the results of your assessments back to you and withdraw you from the study. If you withdraw after three months of taking part in the study, data will be kept for research purposes.

If you consent to taking part in the study, but during the study you lose capacity, the research will be stopped and the data destroyed.

What if there is a problem?

If you have any concerns or wish to complain about any aspect of this project, you should initially contact the researcher, Chloe Herrick, who will do her best to address your concerns. Her contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the University of Birmingham Doctorate course secretary, Karen Kings on 0121 414 7198. The University of Birmingham, as Sponsor of the study, has indemnity (insurance) arrangements in place. Every care will be taken to ensure your wellbeing during the course of this project.

What will happen to the findings of the project?

The findings will help inform the professional literature around how best to differentiate between different memory problems. We also hope it creates better and quicker screening tools which could lead to more timely diagnosis. We hope it will inform services as to how they may best shape their clinical practice. The results will be written up into a report to be submitted for publication in a professional journal which would be available to a large amount of people. The write up will be confidential and you will not be identifiable. If you want to receive a copy of the results, please record your details on the participant consent form so that the researcher can send them to you on completion.

For more information, please contact the researcher:

Chloe Herrick

Clinical Psychologist in training

Department of Psychology

Centre of Applied Psychology

52 Prichatts Road

University of Birmingham

B15 2TT

The project is supervised by Dr Christopher Jones (Consultant Clinical Neuropsychologist & Director of Research for the Doctorate in Clinical Psychology at the University of Birmingham; [redacted] and Dr Mike Ridley-Dash (Clinical Psychologist, Edward Street memory services; [redacted]

Thank you for taking the time to read this information sheet.

Appendix 4: Consent to contact form

Black Country Partnership NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

Participant Consent to contact form

Project Title:

Understanding the differences between dementia and other types of memory problems

You have indicated that you are interested in the research study titled above.

If you consent to being contacted by the researcher for further information, please leave your initials in the box below and record your contact details in the space provided.

	Please initial all boxes
I understand that by leaving my contact details below I am giving the researcher (Chloe Herrick) permission to contact me	
I understand that my contact details will only be used by the researcher the purpose of telling me more about the study and potentially organising in the study	
I understand that my personal details will be destroyed once contact has been made with me	

Name: _____

Telephone number: _____

Convenient times to contact (days of week/times of day): _____

Appendix 5: Participant consent form

Black Country Partnership NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

Participant Consent Form

Project Title:

Understanding the differences between dementia and other types of memory problems

	Please initial all boxes
1. I confirm that I have read and understood the Participant Information Sheet (dated, version number _____) for the above study. I have had the opportunity to consider the information, ask questions and had them answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point of data analysis, without giving reason, and without my care being affected.	
3. I understand that if I choose to withdraw any data collected will be destroyed	
4. I understand that all personal information will remain confidential and that all efforts will be made to ensure that I cannot be identified	
5. I understand that my medical records and relevant sections of data collected during the study may be looked at by responsible individuals from the University of Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data	
6. I agree that data gathered in this study will be stored anonymously and securely on a password protected computer at Edward Street, Memory Services, West Bromwich and The University of Birmingham	
7. I am not currently involved/have been recently involved in other research projects	
8. I understand that the data gathered will be anonymised and published as part of a Clinical Doctorate Thesis and may be published in psychological journals.	

9. I agree to take part in the above study ☐

10. I understand that if I would like to be sent the results of the study then I consent for the researcher to contact me using my postal or email address that I will record at the bottom of this form. I understand that my contact details will only be used by the research team for this purpose and will be destroyed once the report has been sent. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

If you would like to receive a copy of the results of the study, please leave your postal address or email address in the space provided below so that a report can be sent to you. Please bear in mind that this report will not include your personal scores in any of the testing materials. All of the data is anonymised and analysed together to provide an overall study result.

Postal address:

_____

_____

Email address:

_____

Appendix 6: Third party mental health support

Black Country Partnership NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

Third Party Mental Health Support

Project Title:

Understanding the differences between dementia and other types of memory problems

Samaritans

Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout the United Kingdom and Ireland. Every six seconds, Samaritans answer a call for help. They give people ways to cope and the skills to be there for others. They offer listening and support to people and communities in times of need.

You can contact them via:

Telephone: 116 123 (free line)

Email: jo@samaritans.org

Or visit your local branch (find out where your nearest branch is on the Samaritans website)

SANEline

SANEline is a national out-of-hours mental health helpline offering specialist emotional support, guidance and information to anyone affected by mental health problems, including family, friends and carers. They are open every day of the year from 4.30pm to 10.30pm on 0300 304 7000.

Call charges: SANE does not charge for its services but your phone provider may charge you. We have an 0300 number and this means helpline calls are inclusive in allowances on landlines and on mobiles on the same basis as calls to geographic (01 and 02) numbers, or are otherwise charged at a rate that does not exceed the rate for calling an 01 or 02 number. The call charges are set by, and retained by, the caller's phone provider.

Both Samaritans and SANE have websites that also provide more information and methods of support:

http://www.sane.org.uk/what_we_do/support/

https://www.samaritans.org/how-we-can-help/support-and-information/if-youre-having-difficult-time/

Appendix 7: Letter to GP

Letter to GP to request room

[Medical practice address]

Project Title:

Understanding the differences between dementia and other types of memory problems

Dear [medical practice name/ GP],

One of your patients, [name of patient] is interested in taking part in the research project titled above. Participants of the research have been given the option of where they would like to be seen, at home, at the memory services [Edward Street/Bloxwich Hospital/Wolverhampton] or (subject to availability) their GP. An information sheet about this research is attached to this letter.

[Name of patient] has indicated that they would be most comfortable completing the research in a room at their local GP. I am writing to enquire if it may be possible to use one of your rooms for this purpose. The room would be needed for approximately 50 minutes.

Thank you for taking the time to read this letter and consider the use of one of your rooms.

I aim to contact you in the next week by telephone for your response.

Kind Regards,

Chloe Herrick (chief investigator)