Exploring fear of dementia, subjective cognitive complaints and common mental health difficulties in screening for Mild Cognitive Impairment

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This thesis focuses on different factors which might have an effect on screening for Mild Cognitive Impairment and the uptake of cognitive health behaviours which may serve as a preventative health strategy to counter the onset of dementia.

Part 1 consists of a systematic review of existing literature exploring the impact of common mental health difficulties among individuals with subjective cognitive complaints on cognitive decline over time. This identified consistent effects for depression and anxiety on progression to dementia. The importance of a standardised measure of subjective cognitive complaints emerged as part of this review.

Part 2 consists of an original piece of research investigating the effects of online feedback following screening for mild cognitive impairment on fear of dementia, subjective cognitive complaints and general anxiety symptoms. This examines the interaction of these variables in a pre-post design. This part of the thesis also identifies what factors may predict fear of dementia at follow up.

Part 3 consists of a critical appraisal of this dissertation, setting out a number of reflections on the processes of carrying out the empirical paper, the literature review and the contribution Clinical Psychology might make within the public health domain.

Impact Statement

Dementia affects over three quarter of a million people who are living with the condition in the UK (Fernandez et al., 2010, as cited by Lewis, Karlsberg, Sussex, O'Neill, & Cockcroft, L. (2014). Disability caused by dementia is has consequences for societal financial costs, increased burden of informal care and reduced quality of life for people living with the condition as well as their carers (Lewis et al., 2014).

This thesis has explored the role of subjective cognitive complaints, depression, anxiety and fear of dementia in screening for mild cognitive impairment. This project identifies how the above factors have implications for assessment of cognitive complaints, as well as how feedback from screening may inform behaviour change strategies to improve the uptake of cognitive health behaviours.

It is thought that this thesis may have implications for public health strategies, such as the Prime Minister's Challenge on Dementia (2015) and that a potential partnership between the public health sector will enable the insights gathered from this project to translate into general practice. This research identified potential areas of prioritisation for interventions, such as offering interventions to people with a family history of dementia as a first priority as fear of dementia appears to be higher among this population.

This research has also pointed towards the ongoing need to address common mental health difficulties among adults with subjective cognitive concerns, as this appears to be predictive of future cognitive impairment. Collaboration with local providers such as the Improving Access to Psychological Therapies services may enhance the potential impact of the findings of this project. Thorough assessment of the nature of complaints and other difficulties individuals may be having, may enable appropriate interventions which may prevent further disability by cognitive decline later in life.

This research has also identified areas for further development within academia. These include investigating the impact of feedback on fear of dementia at follow up and uptake of recommended health behaviour which may inform further interventions. Research would also be enhanced by attempting to include individuals from more diverse backgrounds.

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Part 1: Literature Review

Common mental health difficulties and subjective cognitive complaints at long-term follow up

Structured Abstract

Background: Subjective cognitive complaints (SCC) offer the potential for early identification of dementia symptoms. Within the literature, mental health difficulties such as depression are frequently identified among individuals presenting with subjective cognitive complaints and mild cognitive impairment (MCI). This review aims to explore the relationship between depression and anxiety difficulties and progression to dementia.

Method: PsycInfo, Medline, Embase and HAPI databases were searched using keywords including SCC, MCI and longitudinal. Papers were included if they reported on data related to SCC, depression or anxiety symptoms and longitudinal data on progression to dementia.

Results: 17 papers were included in this review and incorporated into a narrative synthesis. An association for common mental health difficulties on cognitive decline was identified within 81% of papers included in this review. This review identified significant variation in measurement of SCC which may have implications for the interpretation of the findings in this review.

Conclusion: Common mental health difficulties may have a significant effect on cognitive decline over time. Standardisation of measurement of SCC and evaluating the effect of treatment for depression and anxiety on cognitive decline are recommended as areas for future research and clinical practice.

Introduction

Approximately 50 million people live with dementia worldwide (Frankish & Horton, 2017). Dementia has been identified as a public health priority by the World Health Organisation (2012). Prevention is considered to be a significant component of reducing the prevalence of dementia (Livingston, Sommerlad, Orgeta, Costafreda, Huntley & Ames et al., 2017). The World Health Organisation recognises that some research has shown an association between modifiable lifestyle factors and the development of cognitive impairment (2012). Recent research has branded dementia as the 'most feared disease' (AgeUK, 2015); for both oneself and loved ones contracting the condition. 56% of people reported delaying screening due to fear of dementia (Alzheimer's Society 2017).

Subjective cognitive complaints (SCC) have been of interest in clinical practice and research due to its potentially predictive role in identifying the risk of dementia early. The bridging role of identifying these difficulties early enough allows individuals within the community to access appropriate clinical resources (Buckley, Ellis, Ames, Rowe, Lautenschlager, Maruff et al., 2015).

SCC have largely been presented as precursor to degenerative disorders such as dementia; as part of the Peterson framework for identifying mild cognitive impairment (MCI; Peterson, Smith, Waring, Ivnik, Tamagos & Kokmen 1999). MCI is characterised by having concerns regarding changing cognition; having objective cognitive impairment in more than one cognitive domain; maintenance of functional autonomy in activities of daily living and not having sufficient cognitive difficulty to warrant a diagnosis of dementia (Albert, Thekosky, Dickson et al., 2011).

SCC, on the other hand, is understood to involve having a self-identified complaint of cognitive decline, while still appearing to fall within normative ranges on standardised neuropsychological measures (Mulligan, Smart & Ali, 2016). Across the literature, other relevant terminology has been used to describe similar experiences have included subjective cognitive impairment, subjective cognitive decline and subjective memory impairment. These capture the range of cognitive difficulties which might be indicative of preclinical dementia and MCI, with the consistent factor being the subjective component of the complaint.

Subjective complaints and objective decline

Understanding the implications of different presentations has been considered within La Joie and colleagues' (2016) paper which explores different facets of presenting difficulties among individuals with subjective cognitive complaints (SCC). The importance of early identification was emphasised due to the potential of the effectiveness of interventions at the prodromal or preclinical stages of dementia, where biomarker data may be minimally present. La Joie et al. (2016) recruited participants from community and memory clinic samples resulting in three groups of participants; those who had no reported difficulties, who only presented with subjective complaints and who presented with subjective complaints alongside MCI. Patterns of help seeking were then analysed to explore the relationship between reported difficulties and biomarker data.

SCC was highly related to help-seeking, however complaints related to memory alone were not associated with different objective biological markers. Consistent patterns were identified between the presence of biomarker data which modified the pattern of cognitive difficulties identified on the Cognitive Difficulties Scale (McNair & Khan, 1983, as cited in La Joie et al., 2016). It was thus recommended that cognitive difficulties overall,

not just memory complaints, are assessed at the point of presentation in more detail to improve accuracy (La Joie et al., 2016).

In their meta-analysis of cross-sectional data, Burmester, Leathem and Merrick (2016) reviewed the impact of depression symptoms on objective cognitive performance among adults with subjective memory complaints. This identified a small but significant association between SCC and objective difficulties at cross-sectional time points however difficulties were at times confounded due to the presence of depression and anxiety difficulties. Burmester et al., (2016) acknowledge the need for further research to evaluate the potential influence of depression on outcomes for individuals with SCC.

Common mental health difficulties and co-occurrence with SCC

Mental health problems are understood to significantly contribute to the global disease burden (Vos, Allen, Arora, Barber, Bhutta, Brown et al., 2015). The two most predominant mental health difficulties in the general population are depression and anxiety respectively (Vos et al., 2015). Within the literature, there are a number of incidents of depression and anxiety symptoms co-occurring with SCC, which might serve as a challenge to tease apart presenting complaints (Permann & Storandt, 2005; Jylhä, Melratin, & Isometsä, 2009 as cited in Mascherek et al., 2011a; Balasch, Mordechovic, Shabtai, Giladi, Gurevich & Korczyn, 2013). Within this review, 'common mental health difficulties' will be used to refer to either anxiety or depression, or both.

Anxiety correlates

The presence of anxiety symptoms is frequently acknowledged within the literature, however the impact of its co-occurrence with SCC is understood to a differential degree.

Mulligan and colleagues recognise how individuals with SCC appeared to be classified as the 'worried well'; having their complaints ultimately dismissed (Mulligan et al., 2016). The overlap between anxiety problems and cognitive symptoms has also been noted, with up to 45% of individuals with dementia having identified anxiety difficulties within one cohort (Elfgren et al., 2010, as cited in Delphin-Combe, Bathsavanis, Rouch, Liles, Vannier-Nitenberg, Fantino et al., 2016). Anxiety was found to accelerate the rate of conversion from amnesic MCI to dementia when controlling for depression and cognitive decline, identifying anxiety predominantly as a risk factor for conversion to dementia rather than a prodromal symptom (Mah, Bins & Steffens, 2015).

Depression Correlates

Depression symptoms have also been explored in the literature, particularly at the point of initial assessment. Mascherek and colleagues identified how depression symptoms were found to strongly influence cognitive complaints (Mascherek, Zimprich, Rupprecht & Lang, 2011), while Balasch, Mordechovich, Shabati, Giladi, Gurevich and Korczyn (2012) have reported that scores on the Geriatric Depression Scale were higher among participants who presented with cognitive complaints. The presence of SCC has been found to occur independently of depression symptoms (Burmester et al., 2016), while others argue that SCC with no objective indicators of decline are more reflective of depression than any further difficulties (Mulligan et al 2016; MacLullih et al., 2006 as cited in Burmester et al., 2016).

The interplay between common mental health difficulties, SCC and objective difficulties is also considered of interest. Braun and colleagues (Braun, Schmukle &Kunzmenn, 2017) identified in their review that changes to cognitive functioning were unrelated to any changes self-rated well-being over time. Gulpers et al (Gulpers, Ramakers,

Kohler, Voshar, Volhey 2016) revealed in their meta-analysis that anxiety is associated with an incident cognitive impairment within community settings. Andreescu and colleagues maintained the differences in risk was due to different anxiety, depression and worry profiles; mapping out how this resulted in differential risk profiles within the general population (Andreescu, Teverosky, Hughes, Chang &Ganguli, 2014). The available literature so far presents varying arguments for whether mental health presentations serve as risk factors for further cognitive decline, or whether the presentations of cognitive decline mirror and overlap with common mental health presentations.

Progression to dementia

The importance of understanding the longitudinal impact of SCC on progression to dementia has been considered within two review papers noted to date (Mitchell, Beaumont, Yadegarfar & Stubbs, 2014; Mendonca, Alves & Bugalho, 2016).

Mitchell and colleagues (2014) reported a primary aim of investigating an annual conversion rate for subjective memory complaints to MCI and dementia. The meta-analysis also aimed to report on cumulative percentages for the progression onto dementia from MCI and to evaluate whether conversion rates varied depending on baseline objective cognitive impairment. The study includes articles which reported subjective memory complaints at baseline, had at least six months' follow up and that measured objective cognitive performance at baseline in the presence of subjective memory complaints. Mitchell et al. (2014) reported that, from their sample of 28 datasets, the rate of progression from subjective memory complaints to MCI ranged from 16.45%-34.20% depending on the recruitment site. The annual conversion rate for subjective memory complaints was 2.33%, representing a two-fold risk of developing dementia for individuals with subjective memory complaints. This was significant at $p = 0.001$. Mitchell et al. (2014) reported that the

presence of subjective memory complaints thus has implications for clinical follow up, as self-reported memory complaints appeared to be a risk factor for developing dementia at 4.8 years' follow-up.

Mendoca and colleagues' review (2016) aimed to understand community-based longitudinal studies which evaluated subjective cognitive complaints as a risk factor for mild cognitive impairment and dementia. It included papers which were longitudinal, that presented outcomes as measure of risk and which included a follow up period of 24 months or longer. This review presented findings on 17 included papers, grouping these into two broad categories: those that reviewed SCC as an evolving characteristic of MCI and dementia; and those that evaluated SCC as a co-occurring construct of objective cognitive difficulties. Mendoca et al. (2016) identified that, among adults over the age of 59, subjective cognitive complaints resulted in a 1.5 - 3 times increased risk of dementia, even if controlling for at least two confounding variables. These variables included age, sex, level of education, presence of depression, ApoE levels, race, length of follow-up, chronic health conditions, smoking and alcohol consumption and the number of languages. The specific confounders were not, however, identified within the discussion.

Mitchell and colleagues (2014) did not report on any data relating to depression or anxiety symptoms, and Mendoca and colleagues (2016) identified the evaluation of the impact of depression symptoms on progression to dementia symptoms as an area for future research. The longitudinal impact of depression and anxiety symptoms on the development of dementia, however, remains unexplored within the literature.

The aim of this review is to explore depression and anxiety symptoms among individuals with SCC at long-term follow up when considering progression to dementia.

Method

Search Strategy

PsycInfo, Medline, Embase and HAPI databases were searched for entries containing the following terms or synonyms in the title or keywords: (1) Subjective Cognitive Complaints or Mild Cognitive Impairment (2) Alzheimer's Disease (3) longitudinal (Table 1). Due to the similarity in search strategy to Mitchell et al. (2014), the start date for additional papers was set at April 2014, as this was reported to be the cut off point for publications included within Mitchell and colleagues review. Papers meeting additional depression and anxiety criteria within Mitchell et al.'s (2014) analysis were included in this review. Searches took place between October 2017 and January 2018.

Inclusion and exclusion criteria

Studies were included if they:

- used a standardised psychometric measure to assess cognitive impairment or decline;
- reported on participants who are identified as having SCC at baseline;
- used a longitudinal design;
- reported follow up outcomes;
- included data on depression and/or anxiety;

This review excluded papers which:

- only reported on biomarker data;
- did not report on how MCI was measured;

- involved children;
- were not published in English;

Table 1

Search Terms

	Terms	**Results**
1	SCC OR subjective cognitive complaint* OR subjective cognitive decline OR subjective memory complaint* OR subjective memory impairment	2577
2	MCI OR mild cognitive impairment OR pre-dementia OR amnestic MCI OR preclinical Alzheimer*disease OR prodromal Alzheimer*disease	1824
3	Longitudinal OR progression	3520+997
4	Child OR adolescent	26401+963
5	1 and 2 and 3 not 4	76

Extraction and synthesis

An extraction table was created to capture the following information:

- The country where the research took place

- Sample size, age range of participants and recruitment site
- Method of assessment for subjective cognitive complaints
- Presence of subjective cognitive complaints at baseline
- Assessment of common mental health difficulties and impact on SCC at baseline
- Progression to dementia and associated statistic (percentage, hazard ratio, odds ratio, relative risk)
- Length of follow up
- Statistical effect of common mental health conditions on cognitive difficulties at follow up

Data extracted from the papers in this review were synthesised using a narrative synthesis approach. This aimed to explore the impact of common mental health conditions on cognitive impairment over time. Within the synthesis, commonalities and differences among studies and their measurement of SCC and common mental health conditions were explored. Synthesis also included the significance of the presence of common mental health conditions at baseline and whether these were controlled for at follow up. Relationships among the data were explored, investigating whether there is an effect for depression and anxiety difficulties on cognitive impairment at follow up.

Quality appraisal

The Clinical Appraisal Skills Program (CASP) Cohort Study Checklist (2017) was used to appraise the quality of the eligible studies. This is a 13-item checklist which prompts for appraisals based on:

- the focus of the paper

- the recruitment strategy
- standardized measurement to eliminate biases
- identification and consideration of confounds within the design
- completeness and length of follow up
- the results and their precision identified using confidence intervals
- the application of the results to the local population
- the fit of the results with other available evidence
- the implication of the results

The CASP quality appraisal was applied to all eligible papers to assess for risk of bias and the validity of the papers in pursuit of the research aims. A standardized rating system is not part of the appraisal tool, however papers were categorised as being at low, moderate or high risk of bias. This was determined on the basis of the number of checklist items which were not met or identifiable within the paper. Less than two out of 13 checklist items resulted in papers being assessed of high quality. As the aims of this review were to consider the impact of common mental health difficulties on cognitive decline at follow up; completeness of follow up, identifying and factoring confounds into study design and the use of standardized measurement were weighted more heavily in the rating of risk of poor quality and informed judgment regarding overall bias, including whether something was considered to be at moderate or low quality, for each publication. A summary of the findings from the quality appraisal table can be found in the results section.

Results

After removing duplicates and non-original research, papers that had formed part of and were published after the analysis in Mitchell et al.'s (2014) review and were dated after 1996 resulted in a sample of 48 papers. Papers were then excluded if they did not provide any information on mental health difficulties, if they did not report on the impact of depression or anxiety at follow up and did not report on progression to dementia.

The search and selection strategy yielded a final sample of 17 papers. Figure 1 demonstrates the flow of papers at each stage of selection.

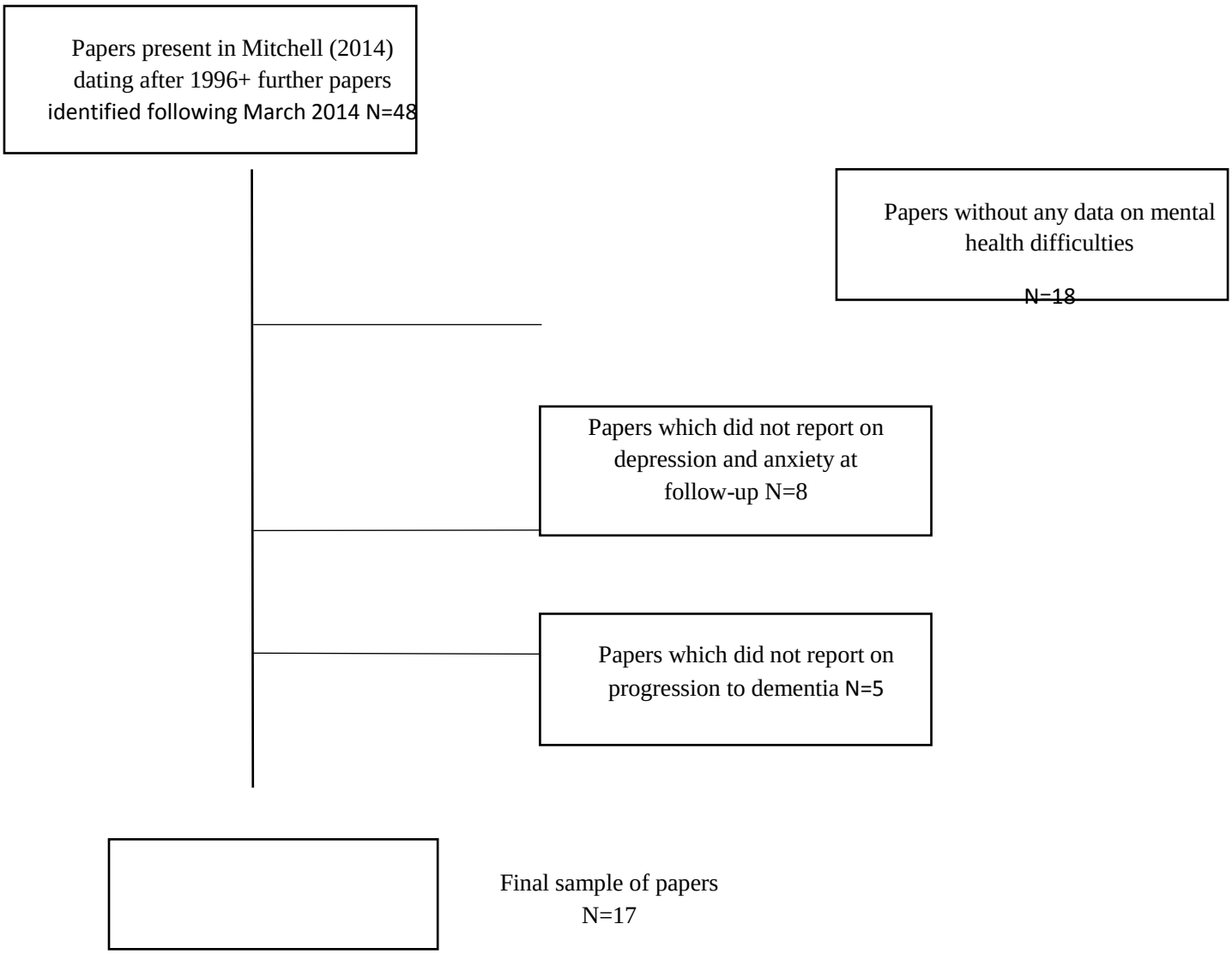

Figure 1. Flow of papers over selection

Findings from quality appraisal

Eight papers (47%) included in this review were considered to be of high quality using the CASP Cohort Study Checklist (2017). Seven papers (41%) were considered to be of moderate quality and two papers (11.76%) were considered to of low quality. The attributed risk of bias most commonly related to measurement of SCC and mental health difficulties, as well as the length of follow up. Jessen and colleagues (2010) identified that a period of time longer than 3.8 years allowed for greater accuracy on estimates for longitudinal research with dementia presentations, which was used as a demarcation of sufficient length of follow up within this appraisal. A summary of the risk of bias ratings for each paper is found in Table 2.

Table 2

Quality appraisal summary

Reference	Quality rating	Rationale
Permann et al 2014	high	No issues identified through the appraisal checklist.
Cherbuin et al 2014	moderate	Difficulties with measurement related to objective cognitive performance and subjective memory difficulties
Roehr et al 2016	high	No issues identified through the appraisal checklist.
Elfgren et al 2010	low	Measurement of mental health symptoms followed subjective reporting of sadness, which is not considered a reliable form of measurement. Follow up not considered sufficient. Confidence intervals not reported and applicability to local population not clear.
Geerlings et al 1999	moderate	Anxiety symptoms not considered to be a potential confound. Length of follow up not considered sufficient.
Jessen et al 2010	high	No issues identified through the appraisal checklist.
Jorm et al 1997	moderate	The age of participants (>70) is not considered applicable to adults with SCC. The findings in this paper are at odds with other available literature, confidence intervals are not reported and the mean follow up period is under 4 years.
Jae Min et al 2006	high	Only length of follow up identified as possible bias issue.
Mol et al 2006	moderate	Measure for SCC not considered valid. Confidence intervals not reported.

		Results reported on change in cognitive performance and did not fit in line with other literature.
Mewton et al 2014	high	No issues identified through the appraisal checklist.
Reisberg et al 2010	moderate	Confounds not factored in to design.
Schofield et al 1997	low	Completeness of follow up considered insufficient. Rationale for drop off in sample numbers explained by 'change in research priorities'. Length of follow up was considered insufficient. Results did not appear to fit in with available literature.
Waldorf et al 2012	high	No issues identified through the appraisal checklist.
Wang et al 2004	high	No issues identified through the appraisal checklist.
Gallassi et al 2010	moderate	50% of sample lost to follow up. Results did not appear to fit with available literature.
St John & Montgomery 2002	moderate	Measurement of SCC was not considered robust. Follow up attrition was not identified within the paper. Confidence intervals were not reported.
Donovan et al 2014	high	Only length of follow up identified as possible bias issue.

Characteristics of studies

The papers in this review were predominantly cohort studies. Most studies were carried out in Western Europe and North America, with one other taking place in South Korea and another in Australia. The length of follow-up ranged from one year to twelve years. All the studies included an assessment of either anxiety or depression at baseline and follow up.

The papers and their extracted data can be found in Table 3.

Characteristics of participants

A total of 17,423 participants were included within this review, with sample sizes in studies ranging from 59 to 3778. The ages for study participants ranged from adults aged 40

and above to adults aged 90. Participants in studies were mostly recruited from population cohort samples with the remainder recruited from outpatient clinics.

Table 3

Characteristics and findings of included studies, in chronological order

(a) **Studies controlling for baseline common mental health problems (depression or anxiety) on the progression of subjective cognitive concerns to dementia (N=12)**

Authors & location	Sample Size and age range	Research design and length of follow up	SCC Assessment	CMH measure and association with subjective cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Progression to dementia, controlling for common mental health problems Statistic and CI
Jorm et al 1997 Australia	N = 945 Age >70Population Sample	Longitudinal study 3.5 years	"Overall, do you feel you can remember things as well as you used to? That is, is your memory the same as it was earlier in life?" Subjective memory decline scale	Goldberg depression and anxiety scale Baseline impact not specified	Not specified	SCC did not predict or were not found to predict dementia at 3.5 years later.	Anxiety and depression associated with past, but not future decline R and R^2 statistic CI not reported

Authors & location	Sample Size and age range	Research design and length of follow up	SCC Assessment	CMH measure and association with subjective cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Progression to dementia, controlling for common mental health problems Statistic and CI
Schofield et al 1997	N = 169 Mean age 75.5	Longitudinal study	'do you have problems with your memory?'	Hamilton depression scale Significant difference in mean scores for SMC group compare (p=0.001)	41.42% had memory complaints	29% of group with memory complaints at baseline had dementia at follow up p=0.001	Depression scores different in SMC group p=0.01 sig OR 2.0
USA	Population sample	1 year					Wald χ^2 statistic CI not reported
St John & Montgomery 2002	N = 1416 Age > 65	Cohort study 5 years	Subjective memory loss (SML) 'Please tell me if you have had memory loss in the past year. You can just answer yes or no.'	CES-D 17.1% of people with SML have CES-D score of >16	21% had SML	SML OR 2.17- 1.82 depending on model	OR for developing dementia at follow up 0.70 χ^2 Statistics
Canada	Population Sample						CI 95% (0.29, 0.61)
Wang et al 2004	N = 1883 Age >65	Cohort Study [what are the groups mentioned in	Subjective Memory Rating Scale (SMRS)	CES-D Mean CES score for SMD group was 6.2 higher than any other group- significantly associated	5% had SMRS score above cut off at baseline, 67% just below cut off	15% with SMC progressed to dementia and associated with cognitive decline at FU	Depression score mean 5.3 at FU for dementia group
USA	Population Sample	5 years					OR for CES-D score 1.10 (CI 1.06-1.15)

Authors & location	Sample Size and age range	Research design and length of follow up	SCC Assessment	CMH measure and association with subjective cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Progression to dementia, controlling for common mental health problems Statistic and CI
Mol et al 2006 The Netherlands	N = 557 Age ≥65 Population sample	Longitudinal Study 2.5 years	‘Do you consider yourself to be forgetful? Have you undertaken any action to remedy your memory problem, apart from possible medication?’	Depression and anxiety subscales of symptom checklist (SCL-90) Correlation of 0.33 for depression symptoms and forgetful groups and for anxiety and forgetfulness of 0.26 (p=0.01)	26.57% identified as 'forgetful', 39 activities to improve forgetfulness , 109 no activities	Self-rated forgetfulness at baseline did not predict change in performance on cognitive measures	No sig difference at follow up reported for depression or anxiety symptoms on cognitive decline.
Jessen et al 2010 Germany	N = 3055 Age ≥75 Population Sample	Cohort Study 4 years	Questions like geriatric mental state schedule “Do you feel like your memory is becoming worse?” Possible answers were “no,” “yes, but this does not worry me”	Geriatric Depression Scale Significant variance in depressive symptoms at baseline between individuals with SMI with and without worry (p=0.001)	Clinical Dementia Rating Schedule Significant variance in depressive symptoms at baseline between groups split by incident SMI of SMC	SMI no worry 41.6% SMI with worry 15.8%	9.7% reported SMC at baseline and 23.5% at follow up 33.2% of SMI went into incident and persistent SMC	4.6% of AD Cases had SMC without worry and 8.2% of SMI with worry 95% CI (2.05-21.23)	OR 12.21 for people with SMC p=0.001 HR : 1.04 CI 0.97-1.13	Baseline SMC associated with incidence of dementia at follow-up in the presence of baseline depression. OR 1.05 (Transient CI 0.15-7.13) 1.62 (Incident CI 0.25-10.6) 2.88 (Persistent CI 0.21-39.0)
Waldorf et al 2012	N = 758	Cohort Study	‘How would you describe your memory?’ 'excellent' 'good' 'less	Euro-Qol 5 Depression subscales	24% reported memory problems at	Positive predictive value of SMC for a dementia	Controlled for CMH		

	Age >65	4 years	good' 'poor' 'miserable'		baseline	diagnosis was 0.14, and negative predictive value was 0.96	No significant effect of CMH problems on hazard ratio for progression to dementia
Denmark	Cohort study			Significant difference between SMC reporters and anxiety and depression severity p=0.01 (CI 0.59-10.26)		Hazard ratio 2.27	

Authors & location	Sample Size and age range	Research design and length of follow up	SCC Assessment	CMH measure and association with subjective cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Progression to dementia, controlling for common mental health problems Statistic and CI
Permann et al 2014 Germany	N = 516 Age 70-103 Population sample	Cohort study 12 years	Geriatric mental state interview + 'how would you judge your memory at the moment?' 5 point rating scale from deficient to good during psychology interview	Hamilton Depression Scale Depression symptoms significantly associated with memory complaints	55% reported SCC at baseline	24.32% converted to MCI 14.18% to dementia	CMH controlled for HR for depression = 0.23 on people with SMC sig= 0.05 CI not reported
Mewton et al 2014 Australia	N = 1905 Age 65-85 Population sample	Cohort study 5 years	Compared with others your age how you you rate your memory? Compared with 5 years ago?	Kesler Psychological Distress Scale Not Specified	13% prevalence at baseline	31% of SMC group worse at follow up	Significant effect at baseline and follow up for negative self-assessed MH OR: 1.4 [CI: 1.0-1.9]
Roehr et al 2016 Germany	N = 453 Age 80.5	Cohort study 8 years	“Do you have problems with your memory?”	German CES-D Higher depression scores among group with SCD	43% stable decline and 38.4% unstable decline	20% of unstable SCD, 42% of stable SCD (1.8HR) converted to MCI/dementia	Significant effect of depression symptoms on stability and progression HR = 1.6 [CI = 1.0–2.3];

(b) **Studies not controlling for baseline common mental health problems on progression to dementia (N=5)**

Authors & location	Sample Size and age range	Research design and length	SCC Assessment	CMH measure and association with (subjective?) cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Other findings
Population sample			p=0.001	(p < .01)	p =< .05		

		of follow up					
Elfgren et al 2010 **Sweden**	N = 59 Age > 75 Clinic Sample	Longitudinal study 3 years	Receiving care in clinic for SMC	Montgomery asberg depression scale, clinical interview, presence of psychosocial stress 33% depressed mood (NS) 71% psychosocial (p=0.001) stress and 63% anxiety (P=0.041)	41% had SMI	Annual conversion rate to MCI 2.9%. None converted to dementia.	Psychosocial stress sig lower among group who did not progress to dementia compared to baseline (p=0.001). Moderate reduction in anxiety (p=0.035) and only slight reduction in depressed mood group.
Resiberg et al 2010 **USA**	N = 213 Age > 40 Population sample	Consecutive series/ longitudinal study 7 years	Complaints of forgetting the location of objects Subjective work difficulties	Hamilton Depression and Anxiety Scales Significant different between groups identified on slowness items in HADS between SCC group	77.79% had subjective cognitive impairment	54.2% of SCI group declined further at follow up p<0.0001	HAM-D slowness items 12.2% decline HR 1.4 p=0.047 Anxiety symptoms 14.48% decline HR 1.6 p=0.004

Authors & location	Sample Size and age range	Research design and length of follow up	SCC Assessment	CMH measure and association with (subjective?) cognitive concerns	SCC presence at baseline	SCC Progression to dementia	Other findings
Gallassi et al 2010 **Italy**	N = 92 Age 60-75 Clinic Sample	Longitudinal study 4 years	Not specified	BDI and STAY No significant differences on baseline depression symptoms, state or trait anxiety between participants in 'converter' or 'non converter' groups	46.7% had SCC only 53.26% had SCC and objective impairment	Only 1 person with no objective impairment progressed to dementia after 4 years	No significant difference for depression and anxiety on progression to objective impairment
Cherbuin et al 2014 **Australia**	N = 305 Age 60-65 Population sample	Cohort study 4 years	'Do you feel you can remember things as well as you used to?'	Goldberg depression and anxiety scale Significant difference for depression symptoms in SMD group at baseline p=0.01	23% SMD wave 1 18% SMD wave 2 13% at both	SMD at wave 2 associated with decline in left and right hippocampal volume SMD at 4 year follow up associated with changes in hippocampal vol.	Correlation on R statistic (p= 0.01) for both anxiety and depression over time at each 'wave' CI not reported

Definition and measurement of SCC

The methods for defining SCC varied between studies. Some papers considered constructs such as 'subjective memory decline', 'impairment' 'complaint' or 'memory loss' (Cherbuin et al., 2014, Elfgren et al., 2010, Geerlings et al., 1999, Jae- Min et al., 2006; Wang et al., 2004; St John & Montgomery, 2002; Waldorff et al., 2012; Mol et al., 2006; Schofield et al., 1999), while others referred to terms which considered broader cognition changes not specific to memory such as 'subjective cognitive impairment or decline' (Roehr et al., 2016; Jorm et al., 1997; Reisberg et al., 2010; Gallassi et al., 2010; Permann et al., 2014). Few papers provided formal definitions for their understanding of subjective complaints related to memory or cognition, this explanation was often incorporated into the method of assessment.

SCC assessment varied over the different studies. Within some studies, a single subjective question such as 'do you have problems with your memory?' was considered sufficient assessment for subjective memory complaints (Cherbuin et al., 2014; Roehr et al., 2016; Geerlings et al., 1999; Schofield et al., 1999; St John & Montgomery, 2002). Other studies incorporated more structured criteria such as decline or difficulty within specific timeframes, as well at the impact of cognitive changes or specific difficulties and the degree of subjective concern (Jessen et al., 2010; Jorm et al., 1997). These studies also tended to include rating scales to allow for scale measurement. Two of the studies (Permann et al., 2014; Jae Min et al., 2006) made use of specific question items from the Geriatric Mental State Questionnaire (Pfeiffer, 1975) which allows for a composite score on subjective memory problems. Donovan et al. (2014) made use of the Clinical Dementia Rating Scale to identify whether participants met criteria for SCC, MCI or established dementia. This was

employed by categorising participants into SCC if they had a sum of boxes score of 0.5 on Memory Judgement and/or Problem Solving, but otherwise performed within typical ranges on other cognitive testing domains.

Wang et al. (2004) produced the subjective memory rating scale, their own measure of subjective cognitive difficulties or memory complaints. This is a five-item scale asking participants to consider changes in remembering names, recognising faces, remembering appointments and noticing the passage of time over the past ten to twenty years, allowing for measurement of change between time points within a larger longitudinal study. Psychometric data on this measure was not reported within this study.

Two papers did not specify how they measured SCC (Elfgren et al., 2010; Gallassi et al., 2010), while one study waited for participants to voice particular complaints regarding memory loss or cognitive changes (Reisberg et al., 2010).

Measurement of Common mental health difficulties

A range of different standardised measures for depression and anxiety symptoms were used across the different studies. The most commonly used measure of depression and anxiety was the Hamilton Depression and Anxiety scale (Hamilton, 1960), with three studies employing this measure. Four scales were used twice in different studies, including the Beck Depression inventory (Beck, 1988), the Geriatric Depression scale (Yesavage & Sheikh, 2008), the Goldberg Depression and Anxiety Scale (Goldberg, Bridges, Duncan-Jones & Grayson, 1988) and the Centre for Epidemiologic Depression Scale (Revised) (Radloff, 1977).

Other measures used to assess depression and anxiety symptoms included the State Trait Anxiety Inventory (Spielberger et al, 1983), the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (First et al., 1994), the neuropsychiatric inventory (Medieros, Robert, Gautheir, Stella, Politis, Leoutsakos et al., 2010), the Kessler Psychological Distress scale (Kessler, Andrews, Cople & Hiripi, 2002), the Euro-Qol 5D depression items (Rabin & de Charro, 2001) and the Montogomery Asberg Depression Scale (Montgomery & Asberg, 1979), alongside an interview regarding psychosocial stressors.

Baseline subjective cognitive difficulties

All but two of the papers in this report identified the proportion of participants with SCC at baseline. The proportions captured the prevalence of subjective memory complaints in twelve papers (St John & Montgomery, 2002; Wang et al., 2004; Waldorf et al., 2012; Schofield et al., 1999; Mol et al., 2016; Kim & Stewart, 2006; Jessen et al., 2011; Geerlings et al., 1999; Elfgren et al., 2010; Roehr et al., 2016; Cherbuin et al., 2014; Mewton et al., 2014) and as broader cognitive complaints in four papers (Donovan et al., 2014; Gallassi et al., 2010; Permann et al., 2014; Reisberg et al., 2010). The proportion of SCC among the overall population at baseline ranged from 5.0% to 79.1% with the mean percentage of SCC within the population being 35.38% [SD 20.38, SE 8.11].

The effect of common mental health difficulties

Difficulties at baseline

Depression or anxiety difficulties were recorded at baseline in all the papers that form part of this review. An association between common mental health difficulties and subjective cognitive complaints at baseline was identified across 12 papers, with depression. There was a significant association between depression symptoms and subjective cognitive complaints in 64% of the papers across this whole review, reporting a significance for this correlation at $p = 0.001$.

Anxiety symptoms were less frequently assessed within the reported studies, with only two studies reporting on the correlation of anxiety symptoms with SCC at baseline at $p = 0.001$ and $p = 0.01$ (Elfgren et al., 2010; Mol et al., 2006). Elfgren et al. (2010) also noted the impact of psychosocial stress in their sample, identifying a significant effect ($p = 0.04$) among the 71% of their sample with SCC who reported psychosocial stress as reported during a clinical interview.

SCC at follow up

The studies including in this review varied in whether they controlled for common mental health difficulties at follow up, with 12 studies doing so out of 17. Odds ratios (OR) for developing dementia among participants with cognitive complaints at baseline, while controlling for common mental health difficulties, were used in three studies included in this review. These were 2.11 and 2.21 and identified in Geerlings et al. (1999) and Jae- Min et al. (2006), respectively. Waldorf and colleagues (2012) reported this as a Hazard Risk Ratio of 2.27.

Descriptive statistics in some papers identified the proportion of individuals who reported SCC at baseline who went on to develop dementia. Roehr et al. (2016) identified that 42.0% of the individuals in their ‘stable’ subjective cognitive decline group developed dementia, with a statistically significant difference to individuals who had ‘unstable’ SCD

or did not have any cognitive complaints at baseline. Jessen et al. (2010) reported that 77.8% of participants in their study reported subjective memory impairment, with and without worry. This was identified as significantly different to individuals who did not report any subjective memory impairment. Resiberg et al. (2010) identified that 54.2% of individuals with subjective cognitive impairment had further cognitive decline at follow up. Wang et al. (2004) reported that 15.0% of participants who had subjective memory complaints at baseline went on to develop dementia, with a significant relationship identified between subjective memory complaints at baseline and presence of dementia at follow up. St John & Montgomery (2002) reported that 15.7% of participants with subjective memory loss developed dementia, with a significant effect of $p = 0.001$. Schofield et al. (1999) identified 29.0% of their sample who had memory of complaints at baseline, who met criteria for a diagnosis of dementia at follow up, with the difference between participants with and without memory complaints significant at the $p = 0.001$ level.

Four studies (Elfgren et al., 2010; Gallassi et al., 2010; Jorm et al., 1997; Mol et al., 2006) did not find a relationship between SCC at baseline and dementia symptoms at follow up. Elfgren et al. (2010) identified an annual conversion rate of 2.9% to MCI symptoms, but not to dementia. The measurement of SCC in each of these papers was considered to be of questionable quality, which may have implications for the sensitivity of the findings.

Cmmon mental health difficulties and SCC at follow up

The association of common mental health difficulties on dementia at follow up takes into consideration the presence of symptoms of common mental health difficulties at baseline, often alongside SCC. An effect for common mental health difficulties was found at

follow up for 8 of the papers in the review which also controlled for common mental health difficulties at follow-up (75%).

A small, but significant, Beta coefficient of 0.23 on individuals with symptoms of common mental health difficulties and subjective memory complaints at baseline, to developing dementia at follow up was found in Permann et al. (2014). This was significant at p=0.05. An OR for subcase depression of 2.07 was identified within Jae-Min et al. (2006). An OR of 0.7 (1.42 for females) for developing dementia among individuals above cut off for depression symptoms was identified in St John and Montgomery's paper (2002).

Significant effects for symptoms of common mental health difficulties on dementia at follow up were reported in a number of papers. Cherbuin et al (2014) reported a statistically significant difference (p=0.01) for individuals with subjective memory decline as well as depression and anxiety symptoms and between those who did not have common mental health difficulties at follow up. Reohr et al.'s (2016) paper reported a statistically significant effect for depression symptoms on the stability of SCC. A mean difference on CES-D scores was noted between the 'stable' group, who consistently reported SCC and were more likely to develop dementia symptoms at follow up, and the 'unstable' group, where reporting of SCC symptoms varied.

Elfgren et al (2010) reported on the relationship between anxiety symptoms, psychosocial stressors and dementia symptoms at follow up. A decline in psychosocial stress was correlated among the group who did *not* progress to dementia. This was significant at p=0.001. Anxiety symptoms were found to be more prevalent among participants whose cognitive difficulties persisted (p=0.035), when comparing among participants reported to be 'persisters' and those whose cognitive difficulties did not persist. Depression symptoms were also found to be prevalent, however this effect was not

significant. Jessen et al. (2010) reported a Hazard ratio of 1 for depression symptoms and the development of Alzheimer's disease, as 15.1% of those who developed dementia at follow up had a Geriatric Depression Scale of over 6 (p=0.01). Mol et al (2006) reported a small (r = 0.33), but ongoing correlation between depression and forgetfulness (p=0.01).

Three studies (Reisberg et al., 2010; Schofield et al., 1999; Wang et al., 2004) only reported a significant effect for SCC on dementia symptoms at follow up. However, these studies also identified a significant effect for depression symptoms at baseline on SCC and noted that these difficulties may be difficult to disentangle.

Three studies (18.75%) did not identify a significant effect for symptoms of common mental health difficulties on the development of dementia at follow up. Waldorff et al. (2012) found no significant difference for depression symptoms on the hazard ratio for progression to dementia. Gallassi et al. (2010) found no significant difference for individuals with identifiable depression and anxiety difficulties on conversion to objective cognitive impairment at follow up. In Jorm et al. (1997) anxiety and depression symptoms were associated with previous decline, but not future decline, suggesting SCC may be a reversible effect.

Discussion

This review aimed to consider the longitudinal assocaition of depression and anxiety symptoms on the development of dementia among adults with SCC. SCC had initially emerged in the research literature on the basis of it forming part of Peterson and colleagues (1999) criteria for MCI. This review has attempted to consider SCC as a construct within its own right, rather than as an accompaniment to objective cognitive decline that would meet criteria for MCI.

This review identified how the measurement of SCC varied widely across the included studies. An association was found between SCC and depression symptoms at baseline in 64% of the included studies, with anxiety symptoms being less-commonly reported. Twelve papers out of 17 controlled for common mental health difficulties when investigating cognitive decline at follow up. Among these 12 papers, 8 studies (75%) found a significant association between having anxiety or depression and SCC at baseline and having dementia at follow up, with one study noting that a decrease in psychological stress was associated with maintained cognitive functioning. Three studies acknowledged that it was difficult to disentangle potential depression symptoms from presenting difficulties of SCC.

Variations in defining and measuring SCC

SCC and its measurement do not appear to be clearly defined within the literature. Archer and colleagues acknowledge how assessment of SCC in clinical as well as research settings is often qualitative in nature and may not provide sufficient psychometric rigour (Archer, McFarlane, Frost, Cutler, Fox & Rossor, 2007). Measurement of SCC in research has not consistently been conducted alongside objective measurement (Burmester et al., 2016), providing inconsistency on the validity of the construct. Recent attempts have been made to standardise research and understanding through the international subjective cognitive decline (SCD) initiative (Jessen et al., 2014). Jessen and colleagues argue that subjective impairments alone should be considered as an early at-risk factor for development of dementia, highlighting the importance of achieving standardisation of measurement to consistently capture its occurrence.

SCC as a construct related to cognitive or memory complaints

Variations were also noted as subjective cognitive complaints often related solely to memory complaints, rather than incorporating the cognitive changes such as executive functioning that may form part of cognitive changes individuals may report. Reisberg et al. (2010) was the sole paper within this review that considered functional changes in a non-memory domain in its assessment of cognitive complaints. The remainder of papers only appear to consider memory changes when discussing subjective cognitive complaints. The validity of subjective cognitive complaints as a construct may be considered questionable. A similar issue was raised by La Joie et al. (2016) in their cross-sectional review of subjective cognitive complaints.

Implications of paper quality

This review incorporated some papers at risk of bias and a few papers deemed to be of low quality. This evaluation of poor quality was largely attributed to the accuracy or validity of measurement of constructs such as cognitive complaints and common mental health difficulties; and the length and completeness of follow up within the respective studies. Interestingly, the papers at considered to be of lower quality(Gallasi et al., 2010; Schofield et al., 1997; Jorm et al., 1997; Mol et al., 2006; Elfgren et al., 2010) presented contradictory findings to the remaining studies featured in this review. The papers of lower quality did not identify any association of common mental health difficulties on cognitive decline at follow up. One potential hypotheses might be the length of follow up within these studies was too short to reflect significant cognitive decline at follow up. Another hypothesis may be that the measures of SCC or the mental health difficulties were not sensitive or specific enough to reflect the presence or absence of these difficulties at baseline or follow up.

Comparisons with other reviews

The longitudinal findings on the development of dementia symptoms from SCC are comparable to those reported in Mitchell et al. (2014) and Mendoca et al. (2016). Six out of 15 papers reported on the proportion of the sample which progressed on to dementia, four papers reported odds ratios while four papers reported no effect. As this review has not statistically analysed the included data, an exact comparison of the overall risk of developing dementia identified from baseline subjective cognitive complaints cannot be estimated from this review.

Mendoca et al (2016) reported that progression to dementia remained consistent even when controlling for confounding variables. Depression symptoms were listed among such possible confounds which were controlled for within the papers that were reviewed. This current review identifies how, in 81% of included papers, depression and anxiety symptoms were associated with dementia symptoms at follow-up.

Mitchell et al.'s (2014) review emphasised the relative impact of subjective cognitive complaints alongside objective cognitive impairments. Among the studies featured in this current review, only 4.6% of individuals with only subjective cognitive complaints appeared to develop dementia. The impact of objective cognitive complaints was not noted within this current review, although the overlap in definitions was identified above.

Papers which have previously explored the relationship between mental health difficulties and cognitive complaints have examined this at cross-sectional time points (Burmester et al., 2016; La Joie et al., 2016). Burmester and colleagues' review (2016)

identified that depression symptoms served as a confounding variable when exploring the relationship between subjective complaints and objective difficulties at cross-sectional time points. La Joie and colleagues (2016) identified how help-seeking and broader cognitive complaints were related to objective cognitive decline. A thorough assessment of cognitive difficulties was recommended to identify potential problems in a timely manner. This review identifies how, while depression and anxiety may contribute to help seeking and cognitive complaints warranting attendance at a memory clinic, the presence of common mental health difficulties does not eliminate the risk of developing dementia in a few years. This review further identifies that treatment for depression and anxiety may minimise the impact of common mental health difficulties on cognitive complaints; potentially reducing the impact of cognitive decline on day to day functioning.

Stability of SCC among participants with mental health difficulties

The stability of the interaction of mental health difficulties and cognitive decline was identified as a potential moderator within some papers in this review. Elfgren et al (2010) identified how difficulties declined with decreased psychosocial stress and Jorm et al (1997) identified how previous depression and anxiety symptoms were associated with past, but not current cognitive impairment. The reversion of cognitive impairment has been explored further in recent literature. In a meta-analysis by Marek Ahmadi (2016) the rate of reversion for subjective cognitive impairment to normal cognition was 24% and higher among population-sample than clinical samples. The diagnostic stability of MCI following cognitive complaints was also explored by Aerts and colleagues (2017). This uncovered that almost half of participants with MCI at baseline did not meet criteria at follow up (Aerts, Heffernan, Kochan, Crawford, Draper, Trollor et al., 2017). Both papers, however, did not

measure or control for the potential role of mental health difficulties on these outcomes. Cines and colleagues explored the converse, exploring whether having an increased awareness of cognitive decline had an impact on psychological distress and found that awareness of increasing cognitive decline was directly associated with decreased mood (Cines, Farrel, Steffener, Sullo, Huey, Karlawish & Cosentino, 2015).

This review has attempted to explore the association of common mental health difficulties and SCC and progression to dementia symptoms. SCC alongside objective impairment or as a singular presentation has been considered within current research. In a meta-analysis of cross-sectional presentations, Crumley and colleagues explored the relationship between subjective and objective memory concerns in older adults (Crumley, Stetler & Horhota 2014). This identified a significant moderate overall effect size between subjective complaints and objective difficulties. Crumley et al. (2014) identified an effect size for SCC and objective difficulties in the context of depression presentations and it was acknowledged as an important area of further study. This synthesis has been able to identify a significant effect for depression at both baseline presentation and follow up. Miebach and colleagues explored patterns of complaints among individuals with depression and identified different patterns of complaints particularly related to the themes of attention fluctuation, affective influence on memory, absence of contextualisation and situational lapses (Miebach, Wolfsgruber, Frommann, Buckley & Wagner, 2018). While this review has identified that common mental health symptoms may have a prolonged effect on further cognitive impairment, treatment for these conditions may potentially ameliorate cognitive difficulties. The interaction between mental health presentations and SCC, however, is yet to be fully understood within the research literature. This highlights the importance of appropriate assessment to fully understand the nature of complaints and identify appropriate interventions.

Variation in measurement

Variation in measurement of SCC has been recognised as a methodological challenge in a number of papers (Crumley et al., 2015; Jessen et al., 2014; Mulligan et al., 2016). The lack of assessment rigour may have implications for understanding prognosis and care planning. This review also identified a range of different assessment measures which were used to identify depression and anxiety symptoms. The measures, as identified above, range from measures such as population screening measures such as CES-D scale, broader measures of psychosocial stress and specific assessment measures which are sensitive to the older adult population. It is arguable that appropriate assessment of common mental health difficulties alongside assessment of cognitive complaints may help identify the specificity of the presenting complaint. The frequency of assessment of anxiety within studies was also lower than the number of studies which included assessments of depression and it is thought that assessment of anxiety symptoms will contribute to a more thorough assessment.

Limitations

The review has provided an overview of the impact of common mental health difficulties on cognitive impairment and progression to dementia. This review has attempted to adhere to the preferred reporting items for systematic reviews and meta analysis (2009), however a number of standards within this review were unable to be met. The analyses within the different studies revealed a fair amount of heterogeneity and the detail of the statistics reported were not consistently available across studies, therefore the decision was made not to run a meta-analysis on the papers included. This review also included papers of heterogeneous quality. Due to time resource limitations, this project was also unable to incorporate hand searching of further papers or second rating of papers in the review by

another reviewer. This project neglected to include search terms related to common mental health difficulties, which may have refined the search process.

Implications

This review has explored the longitudinal impact of common mental health difficulties on cognitive impairment. This review has identified effects for depression and anxiety symptoms on cognitive decline across the majority of the papers included in this review. Discrepancies in the findings are attributable to potential bias in some studies as well as inconsistent measurement of SCC as a construct and presenting complaint. There are a number of implications which may be extrapolated from this review from both a clinical and a research perspective.

Clinical implications

The most pronounced implication that may be drawn from this review is the importance of thorough assessment of subjective cognitive complaints. The emerging consensus appears to be that SCC alone serves as an early warning sign of cognitive decline, perhaps before objective measurement may detect and change (Geerlings et al., 1999; Jae-Min et al., 2006; Jessen et al., 2014; Schofield et al., 1997). A more thorough assessment may involve the use of a standardised measure of cognitive complaints that includes non-memory symptoms such as disorientation, processing speed and executive function changes. An assessment of impact on functioning as well as informant reports may also encourage a more meaningful assessment.

The incorporation of assessment of common mental health difficulties when individuals are identified as having SCC would also be clinically useful. This review

identified that common mental health difficulties among individuals with SCC at baseline has a significant effect on cognitive decline at follow up. Identification of mental health difficulties may present an opportunity to identify appropriate interventions which may minimise the effect of these conditions, and further decline, later in life.

Research implications

This review has also identified areas for further research. The most prominent appears to be the need for a robust and standardised measure of subjective cognitive complaints as the focus of further research. As this review was unable to incorporate a meta-analysis, particularly of the logistic regression data, estimating pooled relative risk of mental health difficulties on dementia at follow up would be recommended as an area for future research.

Some of the studies included in this review had a shorter follow up period. Studies with a follow up period of longer than four years would enable a more sensitive investigation of the effect of common mental health difficulties on cognitive decline. The majority of the studies in this report identified participants lost to follow up due to death and the effects for SCC appeared to be less sensitive among older populations. It would be of interest to consider further investigations with young participants.

Conclusions

Common mental health difficulties such as anxiety and depression have a significant impact on the presence of cognitive complaints at both baseline and follow up. These appear to have implications for the development of dementia symptoms. Addressing mental health difficulties such as anxiety and depression may be one way of reducing the effect of cognitive impairment. This appears to be in line with recommendations suggested Livingston et al., (2017) and the World Health Organisation (2012).

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Part Two: Empirical Paper

What influences Fear of Dementia during online screening for Mild Cognitive Impairment?

Abstract:

Background: Fear of dementia is understood to be influenced by a number of factors and may inform choices individuals make including undertaking advanced directives, as well as engagement with screening for dementia. Screening for dementia may enable engagement with proactive cognitive health behaviours.

Aims: This project aims to explore the effect of feedback on screening for mild cognitive impairment on fear of dementia.

Method: Participants were recruited from a website offering an online cognitive function test offering feedback on cognitive health and recommendations for cognitive health changes. Participants recruited in the study completed measures of anxiety and fear of dementia before completing the cognitive function test and after receiving feedback. 338 cases were available for statistical analysis.

Results: Using analysis of variance analysis, an interaction effect was identified for the feedback category participants were grouped into and fear of dementia scores (p=.000) Using hierarchical multiple regression fear of dementia was also found to be influenced by subjective cognitive complaints, age of participants and family history of dementia(p=.000)The findings from this thesis have implications for health behaviour change strategies as part of the global dementia agenda.

Introduction

The term dementia is used to describe a cluster of diseases affecting the brain which result in progressive cognitive impairment over several years and earlier death (Lewis, Karlsberg Schafer, Sussex, O'Neill, Cockcroft 2014). Around 60,000 people die from dementia each year in the UK (Prince, Albanese, Guerchet, Prina 2014; as cited in Lewis et al 2014). Up to 4.2% of the over 65 population within the UK are estimated to be living with dementia (Public Health England, 2017). Disability caused by dementia is implicated in increased societal financial costs, increased burden of informal care and reduced quality of life for people living with the disease and their carers (Lewis et al, 2014).

Recent research has identified dementia as the 'most feared disease' (AgeUK, 2015); for both oneself and loved ones living with the condition. 56% of people reported delaying screening due to Fear of Dementia (Alzheimer's Society 2017), with people identifying worries about being perceived as mad or becoming a different person following diagnosis. Factors believed to influence the degree of FOD include: personal experiences of dementia and previous caring roles; perceived risk; and perceived ability to cope (Kessler, Bowe, Naer, Froelic &Wener-Wahl 2012). FOD is considered to be separate from health anxiety and trait anxiety (French et al, 2011; Kessler et al 2012).

The concept of 'fear of dementia' first emerged following Cutler and Hodgon (1996)'s description of 'anticipatory dementia', which describes increasing worry related to cognitive changes which may be indicative of later dementia. Fear of dementia (FOD) may be defined as "an emotional response to the perceived threat of developing dementia independent of chronological age and cognitive status" (Kessler et al 2012 p. 277). The concept of fear of dementia is becoming increasingly prevalent in the literature (French,

Floyd, Wilkins & Ostato, 2011), considering factors which may influence fear of dementia as well as how fear of dementia may inform preventative actions, social and health care policy (Corner & Bond 2004).

Factors which may impact fear of dementia

One of the influencing factors for fear of dementia is understood to be proximity to dementia, particularly if living with a family member with the condition. In a qualitative project exploring caregiver's experience of dementia-related worry Jeong Sun and colleagues (Jeong Sun, Eun Ha & Minjeong 2016) identified that fear of dementia appeared to be influenced by observing one's own cognitive decline; comparing one's own behaviour to that of family members; difficulty witnessing family members' experiences; feeling lost in the disease process and a sense of hopelessness about the future. Jeong et al's (2016) research also identified how participants made efforts to attempt to reduce their risk of dementia by increasing their awareness and making lifestyle changes. Witnessing a parent die following severe dementia has also been linked to a preference for end of life decision-making (Terman, as cited in Volcier, 2016).

Fear of dementia is thought to play a role in decision making and wellness behaviours. Volcier (2016) identified how advanced directives appear to be informed by fear of dementia, which may subsequently lead to premature loss of life if individuals chose to end their life before the onset of advanced dementia. The drivers of such consequences may also be what is informing such perspectives and worry. In a systematic review by Anderson and colleagues (Anderson, Day, Beard, Reed & Wu, 2009), it was identified how

the majority of knowledge available in the public domain is related to Alzheimer's disease rather than maintaining cognitive health.

In a scoping review on public perceptions of risk and protective factors, Friedman and colleagues (Friedman, Becofsky, Anderson, Bryant, Hunter, Levy et al 2015) summarised findings from 34 ranging studies, identifying what participants considered to be risk factors for dementia, as well as factors which were considered to promote cognitive health. Older adults within the review appeared to attribute memory loss more frequently to stress, genetic influences, brain injury and chronic illnesses (Laditka et al 2013, as cited in Friedman et al 2015). Participants also identified how social and mental engagement were protective (Wu et al 2009; Friedman et al 2011 as cited in Friedman et al 2015). Variations in understanding of causal and protective factors were noted among participants from minority ethnic backgrounds. Participants within the reported studies also appeared to have a limited sense of control over future development of dementia symptoms.

The role of screening in dementia

The sense of control and predictability over future diagnoses can be considered as part of the discussion around screening for health issues such as dementia. The improvement in biological and genetic screening markers, as well as refinement of psychometric testing for mild cognitive testing has resulted in an increasing discussion on the role of screening within the literature. In a summary following a patient and public involvement event in the UK, Martin and colleagues (Martin, Fleming, Cullum, Dening, Rait, Fox et al 2015), identified participants' perceptions regarding screening as well as factors which might influence one's decision to undertake screening for dementia. The themes from the findings were organised into responses related to the pre-screening, in-screening and post-screening

processes. Existing care, health status and prior experiences of screening assessments appeared to play a salient role for participants, while the logistics around screening, relationship with health professionals and awareness of the disease were considered to be influential during screening. A number of factors were considered to play a role following screening, including stigma related to the diagnosis, changes in lifestyle, planning for the future and the role of support. Albeit a complex issue, Martin and colleagues' (2015) findings identified that screening might be considered an acceptable process, however this was influenced by one's experiences, attitudes and beliefs (Martin et al, 2015).

The efficacy of screening in primary care was also recently reviewed by Eichler and colleagues (Eichler, Thyrian, Hertel, Michalowsky, Wucherer, Dreier et al 2015). This study revealed that routine screening enabled an increase in identifying cognitive impairment by 30%. At the time of publication, there was little reported evidence of improved outcomes for individuals who had received an earlier diagnosis. Eichler and colleagues noted the importance of observing longitudinal outcomes which are still due to be published (2015).

In a scoping review relating to issues pertaining to screening for dementia, Hughes and colleagues (Hughes, Ingram, Jarvis, Denton, Lampshire & Wernham, 2017) identified four themes: stigma, ethics, burden and language. The theme stigma related to both internal and external discrimination, including interpersonal and workplace challenges, difficulties taking out insurance policies and social withdrawal. Stigma was also identified towards carers of people living with dementia. The ethical challenges identified within this review centred around the clinical utility of a 'pre-dementia' diagnosis in the context of uncertain outcomes following such a diagnosis. The helpfulness of early diagnosis has also been

called into question, particularly within the context of perceived limited interventions. Hughes and colleagues also considered the psychological impact of receiving a pre-dementia diagnosis, and considered the impact of this alongside pre-existing depression and anxiety difficulties and the potential risk of suicide following biomarker identification. Clear communication, identified through the theme 'language', considered the process of discussing and disclosing pre-clinical diagnoses as well as the current language used to describe the biological pathology and nature of the condition.

The role of anxiety in clinic presentations for cognitive complaints, while discussed in detail in the literature review, is also considered relevant to this study. Delphin-Coombe and colleagues (Delphin-Coombe, Bathsavanis, Rouch, Liles, Vannier-Nitenberg, Fatino et al 2016) identified how, for a proportion (9%) of participants attending a memory clinic, that anxiety has an effect on specific memory difficulties. The report identified that concerns about memory problems require disentangling to identify the source of complaints and assign appropriate interventions. Psychological factors such as common mental health difficulties and personality factors have been implicated in the number of complaints among older adults (Slavin, Brodaty, Kochan, Trollor, Draper & Sachdev 2010). A relationship between subjective memory complaints and low memory self-efficacy was identified by Lucas et al (2017), which may have implications for the uptake of proactive coping strategies. Cines and colleagues (Cines, Farrell, Steffner, Sullo, Huey, Karlwish et al, 2015) identified how awareness of memory failures have been associated with depressed mood. Awareness of memory failures was also associated with increased fear of dementia in the previously discussed research on caregivers' experiences (Jeong et al 2016). However, fear of dementia may also result in increased monitoring of cognitive errors, leading to an over-estimation of cognitive concerns (Kessler et al., 2012).

Fear of dementia and screening practices

The role of emotional processing, including fear of dementia, is important to understand in relation to screening for conditions such as dementia and undertaking recommended lifestyle changes which may ameliorate its effects. Michie and colleagues' (Michie, Stralen & West 2011) model of behaviour change maintains that behaviour exists as an interaction of three necessary conditions. These are capability; the psychological or physical ability to carry the behaviour out, motivation; the reflective and automatic mechanisms to activate or inhibit the behaviour, and opportunity; the physical and social environment which may enable a behaviour. It is plausible to consider that fear of dementia may influence uptake of screening and behaviour changes on the 'capability' and 'motivation' level. In contrast to the hypothesis that FOD acts as a motivator to engagement in cognitive health protective behaviours, high levels of fear may instead be associated with screening avoidance and a denial of the need for lifestyle change. Thus it is hypothesised that fear of dementia can play a role in individual choices regarding screening and making lifestyle changes that may minimise the impact or onset of dementia later in life (Kessler et al 2012).

The role of preventative health behaviours

In the absence of an available cure for dementia, the World Dementia Council (WDC) emphasised the importance of dementia risk reduction, identifying it as a critical element of the global dementia agenda in 2015. This highlights the importance of more research to clarify the relationships which exist between individual risk factors and dementia risk, as well as the effectiveness of targeting modifiable risk factors such as diet, exercise

and lifestyle factors such as smoking tobacco and alcohol consumption (Marsden & Mestre-Ferrandiz, 2015). Modifiable risk factors are believed to be affected by behaviour changes at population level, with the World Alzheimer's report (Prince, Albanese, Guerchet & Prina 2014) suggesting that preventative action targeting this may result in meaningful change.

The current NICE public health guidance (2015) recommends promoting behavioural change for middle age groups in order to reduce the risk of dementia. Cognitive health behaviours are defined as actions and practices which are understood to protect against cognitive decline (Trustram Eve & de Jager, 2014). These include lifestyle factors such as remaining physically, mentally and socially active, and dietary factors such as eating a diet high in omega 3 and antioxidants, minimising sugar and refined foods, supplementing B vitamins and limiting coffee.

Engagement with health behaviour programmes

One proposed response is to deliver health behaviour programmes using eHealth interventions. Offering interventions through eHealth has the potential to support health behaviour change due to its potential as an accessible, personalised and flexible resource. It is expected that an online intervention will suit a substantial and growing group and may provide an individualised intervention which may benefit a significant number of people who may be reluctant or unable to engage with an in-person programme. However, further research is required to understand people's motivation to seek out and engage with such interventions. One publicly available eHealth intervention intending to support health behaviour change is available on the Food for the Brain (FFB) website. The site includes an online cognitive and lifestyle assessment and visitors to the site who complete the assessments are provided with feedback on their cognitive performance using a metric

called the Cognitive Function Test (Trustam Eve & de Jager 2014) and are then given recommendations for lifestyle change.

Although the intention of FFB is that the feedback should motivate site visitors to engage in cognitive health protective behaviours, results from a survey of site visitors indicates that many do not take action. Recent data revealed that less than 4% of visitors visited a GP after taking the test and just over 25% of respondents made behavioural or lifestyle changes after completing the screening tool (Aguirre, Copeman, Curtis & Charlesworth, in press). It is of interest to explore both motivators for engaging in screening, as well as factors which may influence the uptake of cognitive health behaviours.

Rationale and aims

There is increased knowledge regarding the role of modifiable lifestyle factors in the prevention of dementia (Farrow, 2008; NICE 2014) and an increased emphasis on preventative action (Lincoln et al., 2014). However, there is wide variation in the extent to which people engage with lifestyle change initiatives. Fear of dementia may be important in understanding people's cognitive health protective behaviours. However, this hypothesised relationship has not yet been the subject of empirical investigation.

In this research, the aim is to study the impact of cognitve function feedback on fear of dementia.

For people who are motivated to self-screen for cognitive impairments using the 'Cognitive Function Test' (CFT) and lifestyle assessment on the 'Food for the Brain' (FFB) website

- what factors influence fear of dementia?
- What is the effect of receiving feedback on the CFT on fear of dementia?

Method

Design

This project made use of a repeated measures design using online questionnaire data from members of the general public who had visited the website of a UK charity which offers assessment of cognitive function and provides lifestyle advice.

Participants

Recruitment procedure

Participants were recruited in collaboration with the charity Food for The Brain (FFB). This project formed the first 'wave' of an ongoing research project in partnership between UCL and Food for the Brain exploring the utility of eHealth interventions to support health behaviour change. Subscribers to FFB's email mailing list were emailed by the charity to invite them to participate in this research project. Potential participants were also signposted to information about the research project through an advertisement banner on the FFB website and through social media channels.

The advert for the project contained a hyperlink to an information sheet and consent form (see appendix A). People interested in the project were then prompted to questions which helped identify whether participants met the inclusion criteria of the study and were then invited to consent to their involvement in the study if they met the inclusion criteria. Participants completed baseline measures on a UCL-hosted Qualtrics webpage. On completing these, participants were redirected to the FFB website to complete the Cognitive Function Test, subjective cognitive complaints questions, demographic information and a lifestyle and diet questionnaire. Participants who had completed this and who consented to

be contacted for future research were then sent an email within 24 hours with a prompt to complete a follow-up questionnaire which included both the questionnaires on the Qualtrics platform and the data collected on the FFB website.

Eligibility criteria

Participants were eligible for inclusion in this project if they were

- between 50 to 65 years old;
- able to use and access a computer and the internet;
- able to read and respond to eligibility questions.

The exclusion criteria for this project included:

- Self-reported previous attendance at a memory clinic;
- Having a diagnosis of dementia;
- Having a history of neurological or psychiatric conditions likely to substantially affect cognition (for example, recent stroke, epilepsy, schizophrenia); and,
- Having sensory deficits or mobility limitations that would prevent or substantially restrict ability to undertake the assessment or engage with the lifestyle advice provided.

Power calculation

Power analysis was conducted using the G-Power Analysis tool. For the regression analysis, aiming to identify a small effect size on the tested 4 predictors with a power of 0.9.

This identified a required total sample size of 313 participants. For the analysis of variance, for a small effect with a power of .9 a sample size of 54 was identified.

Materials

Cognitive function test

This study aimed to explore the effect of receiving information about one's cognitive health on measureable fear of dementia. Cognitive health information was provided by means of the cognitive function test. The Cognitive Function Test (CFT) is an online, self-administered test that assesses three cognitive domains which are understood to be sensitive to or predictive of Alzheimer's Disease (Welsh et al., 1992, as cited in De Jager et al., 2003), specifically episodic memory (Grober and Kawas, 1997; Chen et al., 2000; Hänninen et al., 1995, as cited in De Jager et al., 2003), executive function (Tierney et al., 1996) and processing speed (De Jager et al., 2003). The CFT includes a novel free and cued placing recall test with paired associate properties based on the Placing Test (Anderson et al., 2006, as cited in De Jager et al., 2003).

The online CFT has been validated, in a pilot study, against the best available paper and pencil tests used in memory clinics with a correlation of 0.75. (Trustam Eve & de Jager 2014). The CFT is a valid and reliable measure of cognitive performance for adults aged between 50 and 65 (Trustam Eve & de Jager 2014). Following the test, the CFT identifies the range of one's scores in relation to one's age. This is categorised into one of three categories 'green' indicating little to no cognitive impairment with a score of 110-43, 'amber' identifying potential risk for cognitive impairment with a score of 42-38 and 'red' which identifies Mild Cognitive Impairment (MCI) with a score of 37 or lower.

Primary outcome measure

- ***Fear of Dementia (FOD)* scale** is a 12-item measure of general fear about developing dementia. The FOD scale is derived from the General Fear subscale of the Fear of Alzheimer's Disease scale (FADS; French et al., 2011). The response format for each item is a 5-point scale of never, rarely, sometimes, often, always (Appendix III), giving scores from 0 (never) to 4 (always), with the range of potential scores for the measure ranging from 0-48.

A 17-item FOD scale was first used by Pak (2015), having adapted the FADS questions by replacing the term 'Alzheimer's Disease' with 'dementia' in each question. Analysis of the psychometric properties of the 17-item FOD, completed online by 295 people aged between 45 and 79 (mean age 57.3 years, SD 7.46), demonstrated that the full range of response options was used for each item (Geiger, 2016). However, some inter-item correlations were very high ($r>0.9$), and the determinant of the R-matrix was less than .00001, indicating multicollinearity (Field, 2005). Following inspection of the R-matrix, five highly correlating items were removed to produce a 12-item scale, for which the determinant was adequate (0.00001197), indicating that multicollinearity was no longer a concern. The Kaiser-Meyer-Olkin measure of sampling adequacy (KMO= .961), and the highly significant Bartlett test of sphericity (approx. chi-square =3277 $p<0.000$). indicated that factor analysis was appropriate for the data. Inspection of eigenvalues and screeplot indicated that the data was best explained by a 1-factor solution, accounting for 70.4% variance.

Data on fear of dementia was collected at baseline (time 1) and after participants had

received feedback on their performance on the Cognitive Function Test (time 2). Cronbach's Alpha for the 12-item FOD at time 1 of the current study (N=338) was .962, demonstrating a high level of internal consistency.

Secondary measures

- **Generalised Anxiety Disorder-7 scale (GAD-7)** As individual levels of anxiety may be conflated with FOD scores (French et al, 2011; Kessler et al 2012) a measure of overall anxiety was used to measure the relative impact of this variable. The GAD-7 is a seven item questionnaire about anxiety symptoms experienced in the last two weeks (Spitzer, Kroenke, Williams & Lowe 2006). Individuals are asked to rate how "bothered" by a range of anxiety symptoms on a four-point Likert scale ranging from "not at all', scoring as 0, to "almost every day", scoring a 3. Participants thus receive a score of between 0 and 21, with scores of over 5 being indicative of clinical levels of anxiety difficulties. Scores on the measure have good internal consistency and good procedural validity. The GAD-7 is routinely used in IAPT services within the UK and has adequate sensitivity (83%) and specificity (84%) for the detection of generalised anxiety disorder using a cut-off score of ≥ 8 (Plummer, Manea, Trepel, & McMillan, 2016). Participants were asked to complete the GAD7 before and after completing the cognitive function test.
- **Subjective cognitive complaints**: Participants were asked six questions about subjective cognitive concerns. This included questions about whether participants had any concerns about their memory, whether participants forgot names of close friends or relatives, whether participants forgot where they placed things, words that they may have been looking for, whether participants have become lost in unfamiliar

settings and whether participants' family members reported any concerns about their memory. Participants were prompted for a yes/no response to these items and the total 'yes' responses were added into a total score for cognitive complaints. The range of possible scores was 0-6. This was collected through the FFB website as part of the CFT test.

- **Lifestyle questionnaires:** Self-reported lifestyle habits formed part of the questionnaire developed and embedded in the CFT questionnaire. Variables were selected based on the available evidence in relation to risk factors for Alzheimer's, and focus on the six prevention steps as described on the CFT. It includes current amount and type of physical, mental and social activity and a range of questions related to dietary practices. This was collected through the FFB website. The data from these questionnaires was not used within this analysis, however, participants received tailored feedback on these responses in line with the category they were grouped into on the CFT.
- **Demographic information:** Participants were asked about whether they had a family history of dementia, whether they were employed and for information regarding their ethnic background and their identified gender.

Data screening and cleaning

The data were gathered from the Qualtrics and Food for the Brain web pages in three separate excel sheets. Data were checked for duplicates, extraneous variables were removed and data was then merged onto one data file on SPSS for analysis.

Prior to statistical analysis, data were examined for input errors, missing values, normality, and violations of assumptions of regression analyses. Cases were removed where responses identified ineligibility for the study and with missing data of more than 5% per variable. Little's Missing Completely at Random (MCAR) test (Little, 1988) was used to identify whether data were MCAR. Missing data on the FOD scale and the GAD7 were substituted using mean values. It was not possible to substitute missing data on variables for gender, ethnicity and employment status.

Normality was investigated by examining z-scores for skewness and kurtosis. Data were considered to be normally distributed if z-scores were less than 2.58 ($p > .01$). Pearson's correlations between predictor variables were used to assess multicollinearity alongside variance inflation factors (VIF); correlations among predictor variables should be less than .90 (Tabachnick & Fidel, 2007) and the VIF should be less than 10 (Myers, 1990). The assumptions of normality were violated for GAD7, FOD and CFT scores, thus nonparametric equivalents were employed for multivariate analysis.

Analyses

Descriptive statistics were used to explore data for the fear of dementia scale, GAD7 scale, total subjective cognitive complaints and scores on the CFT at time 1 and time 2. Descriptive statistics were also used to identify fear of dementia scores according to individual subjective cognitive complaints. Correlations using Pearson's r were run to explore the relationship between these variables at time 1 and time 2.

Graphical representation was used to explore the data and the mean scores on the FOD scale, GAD7 and total subjective cognitive complaints at time 1 and time 2, exploring the variance of scores based on participants' score category on the CFT.

Friedman's ANOVA was run with FOD, GAD7 and SCC total scores as two level dependent variables and categories on the CFT as an independent variable with three levels.

Further analysis involved a hierarchical regression, with post-feedback (time 2) FOD as the dependent variable with demographic variables as one block, subjective cognitive complaints, baseline GAD7 and FOD scores as a second block and CFT score categories as a third block. Data were analysed using IBM Statistical Package for Social Sciences (SPSS) version 22.

Ethics

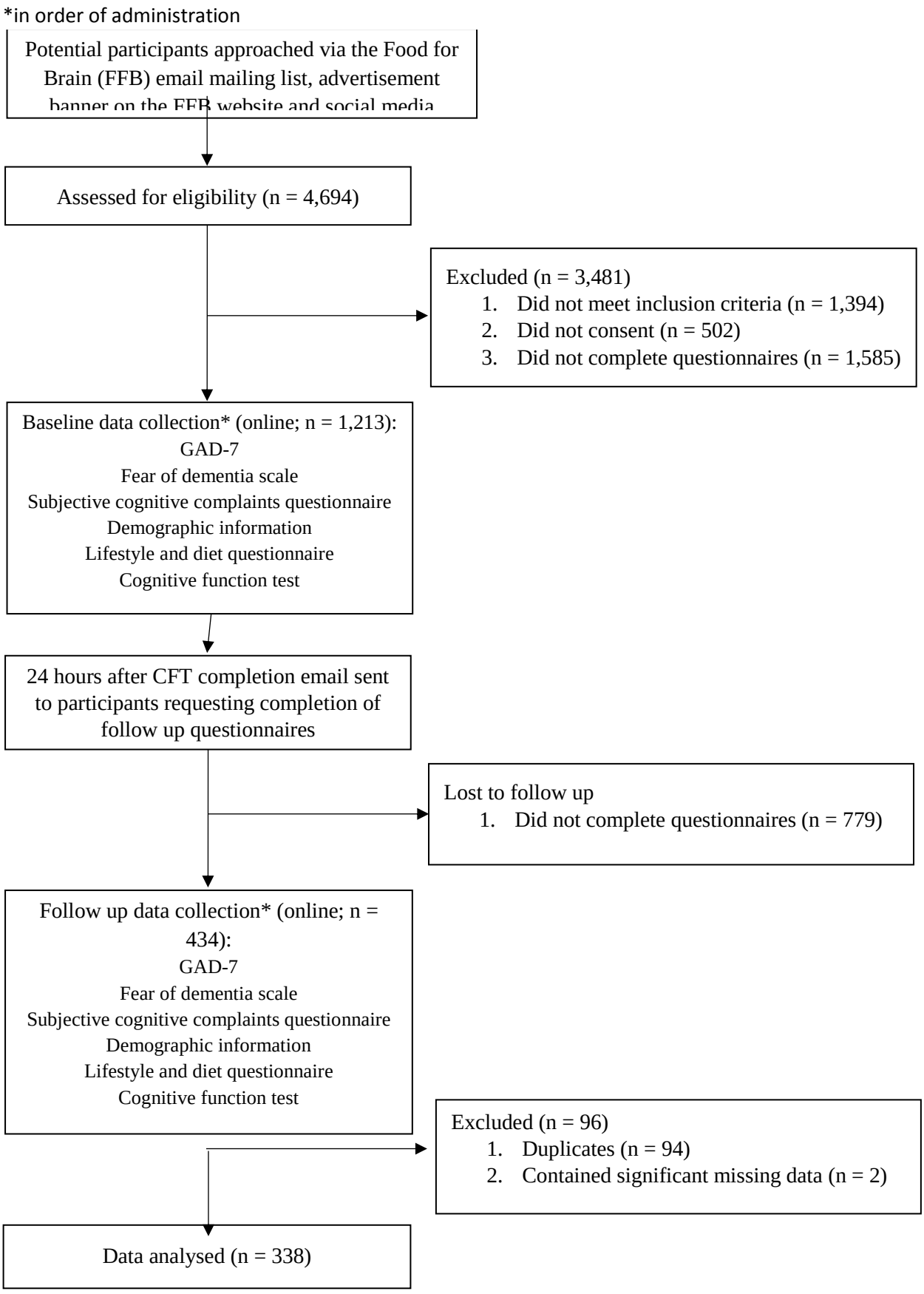
This project was granted ethical approval by the UCL Division of Psychology and Language Science (CEHP/2017/563). The ethical application for this project formed part of a wider application to evaluate the implementation of an online cognitive function test. A copy of the ethical approval letter can be found in appendix B.

Results

Recruitment and participant flow

Recruitment began in December 2017 and ended in mid-April 2018. 2,374 participants identified as meeting the inclusion criteria and consented to participate in the study via the UCL Qualtrics page. 1413 participants followed on to the Food for The Brain website and 1213 completed the cognitive function test. 434 participants followed an email prompt sent 24 hours later inviting participants to complete the UCL questionnaire data once more as a follow up, considered as time 2 within this project. Following the merging of data files from the FFB recruitment, and matching pairs for time 1 and time 2, there were 338 cases of participant data available for analyses. Data were included from participants who completed the CFT and completed two time points of the FOD and the GAD-7. A flow diagram depicting the number of participants at each stage can be found in figure 1.

FIGURE 1: DATA COLLECTION AND ANALYSIS FLOW CHART



Data screening and cleaning

Missing data were considered significant if more than 5% of the scores on a measure were not encoded. There were 2 (0.5%) cases with significant missing data which were removed. 338 cases of participants remained after data screening and cleaning.

Data cleaning

Nineteen participants (5.6%) had missing data items on the FOD scale and the GAD7. There were no case variables with 5% or more missing values on individual questionnaire items. Using Little's missing completely at random test (Little, 1988), it was established that the missing data was random (χ^2 =10.18, p = .990). Missing data on the FOD scale and the GAD7 were substituted using mean values of other scores on the questionnaire at that time point. There was also missing data in 1.5% -8.9% of cases on the categorical variables for gender, ethnicity and employment status. It was not possible to substitute missing data on these items.

Data distributions

Non-parametric equivalent tests were run in the place of multiple analysis of variance as the skew of scores on the CFT (Z=4.81), GAD7 (Z=10.09) and FOD (Z= 2.67) fell beyond indices of acceptance limits (Field, 2014). Data was not transformed for the regression analysis as the assumption of homoscedasticity was not violated.

Demographic information

Demographic information for participants included in this study can be found in Table 1.

Table 1

Demographic details of participants included in the study.

Demographic		
Age	**N** 338	**Mean (SD)** 57.13 (4.14)
	N	**%**
Ethnicity		
White British or Mixed British	234	69.26
Other White	61	18.04
Other/ Mixed Heritage	6	1.77
Black/ Black Caribbean	2	0.59
Asian including Chinese	5	1.47
Missing	30	8.87
Gender		
Male	66	19.5
Female	257	76
Missing	15	4.5
Employment		
Full Time	102	30.2
Part Time	98	29
No	133	39.3
Missing	5	1.5
Family history of Alzheimer's disease		
No	195	57.7
Yes	143	42.3

Descriptive data

The means, standard deviation and range data for measures of subjective cognitive complaints, fear of dementia and general anxiety symptoms at Time 1 and Time 2 are presented in table 2.

Table 2

Mean, standard deviation and range on the SCC, FOD and GAD7 scale at time 1 and time 2

		Mean	SD	Range
Time 1	**SCC**	2.48	1.50	0-6
	FOD	33.59	11.85	12-60
	GAD7	4.64	4.56	0-21
Time 2	**SCC**	2.47	1.48	0-6
	FOD	31.97	11.78	12-60
	GAD7	4.10	4.39	0-20

Bivariate Analysis

To provide an understanding of the relationship between subjective cognitive complaints, CFT scores, GAD7 scores and FOD scores at baseline and to assess multicollinearity, Pearson's r correlations were conducted between each of these variables. There were positive correlations between baseline subjective cognitive complaints and anxiety symptoms as measured on the GAD-7. There were positive correlations between GAD7 scores and fear of dementia scores at time 1.

Correlations were also run between variables at Time 2, with small correlations for anxiety and cognitive complaints and for subjective cognitive complaints and fear of

dementia scores. Moderate correlations were found for fear of dementia symptoms and general anxiety symptoms. A full illustration of correlations at can be found in table 3.

Table 3

Correlation data

	CFT	SCC 1	GAD7 1	FOD 1	SCC 2	GAD7 2	FOD 2
CFT	-	-.022	-.016	-.016	-.043	-.018	-.041
SCC 1		-	.128*	.093	.921**	.305**	.343**
GAD7 1			-	.475**	.138*	.115*	.098
FOD 1				-	.096	-.044	.185**
SCC 2					-	.325**	.356**
GAD7 2						-	.514**
FOD 2							-

***. Correlation is significant at the 0.05 level (2-tailed).**

****. Correlation is significant at the 0.01 level (2-tailed).**

N=338

Fear of Dementia Scores at baseline

The mean scores for FOD at baseline in accordance to the different predictors and demographic variables are presented in table 4.

Table 4

Baseline FOD scores

	N	FOD Mean	SD
Fam. History Yes	143	35.43	11.54
Fam. History No	195	32.25	11.92
Male	66	32.02	11.00
Female	257	33.9	11.82
SCC Fam. concerns	109	34.83	12.6
SCC Lose way	25	34.00	10.71
SCC Forget words	250	34.01	11.86
SCC Forget things	194	34.73	12.16
SCC Forget names	52	33.15	11.74
SCC Mem concerns	207	34.14	12.45
CFT Green	293	33.48	12.08
CFT Amber	20	35.5	11.73
CFT Red	25	33.4	9.21

Participants appeared to endorse word forgetting and memory concerns most frequently of all the cognitive concerns listed. Scores on the FOD scale appear to be higher among individuals who endorsed forgetting things and family members having concerns regarding their memory.

Multivariate Analysis

An interaction effect was noted when exploring scores on FOD, GAD7 and SCC categories of feedback on the CFT and time. Figures 2-4 below illustrate the different mean among participants in each category for of the CFT for each time point.

Figure 2 mean scores for FOD at time 1 and time 2 by participant CFT category

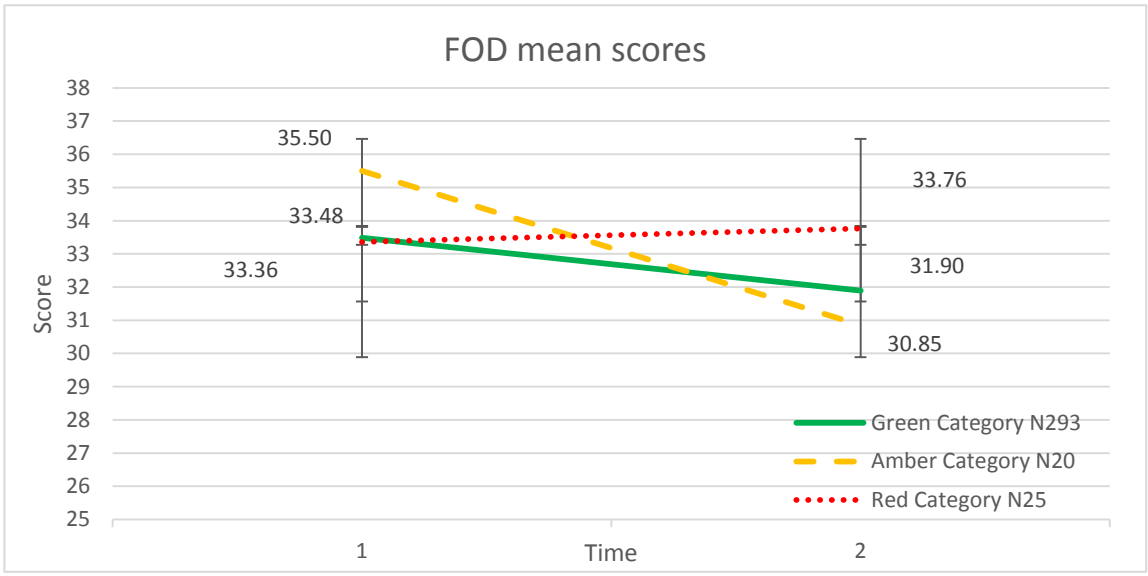


Figure 3 mean scores for SCC at time 1 and time 2 by participant CFT category

	CFT Green	CFT Amber	CFT Red

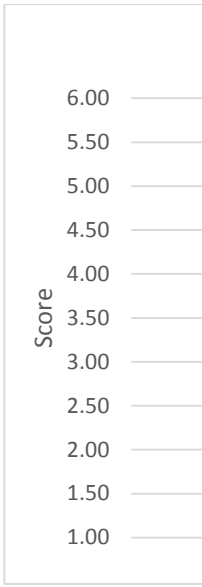


Figure 4 mean scores for GAD7 at time 1 and time 2 by participant CFT category

ANOVA

Friedman's ANOVA was run to explore the interaction between scores across time 1 and time 2. FOD, GAD7 and SCC scores were the dependent variable and categories on the CFT were the independent variable. A significant difference was found between the scores (χ^2 (8) 1783.91 *p*=.000, *Kendall's W* effect size= .660). Pairwise comparisons were run among the variables. Bonferroni's post hoc correction was run to minimize the risk of Type I error. Table 5 below illustrated the pairwise comparisons and their significance.

Table 5

Standardised test statistic for pairwise comparisons

FOD1	20.03*	28.48*	27.88*
FOD2	20.46*	28.23*	28.23*
GAD71	1.27	11.66*	9.13*
GAD72	1.29	10.21*	10.03*
SCC1	1.27	9.3*	9.14*
SCC2	1.28	9.31*	9.13*

N=338

***Significant at .000 level**

Variables influencing Fear of Dementia Scores

Hierarchical linear regression analyses were carried out to examine the extent to which scores on the cognitive function test statistically predicted fear of dementia scores at time 2. Demographic information related to age at testing, gender and family history of dementia were entered at step 1, baseline sores on the GAD7, FOD and the total subjective cognitive complaints score were entered in step 2 and CFT scores were entered into step 3, with fear of dementia scores at time 2 as the dependent variable.

The demographic block was a significant predictor of FOD (F=11.72 df1= 2, df2=335, R^2=.065, p=.000) accounting for 6.5% of the variance in FOD score. In model 2, adding baseline subjective cognitive complaints, FOD scores and anxiety symptoms, also contributed to significant variance for fear of dementia scores at time 2(*F*=16.39, df1=3, df2=332, R^2=.186, p=.000), accounting for 18.6% of the variance in FOD scores at time 2. The R^2 change between model 1 and model 2 was 0.121, revealing a 12.1% increase in

significant variance between model 1 and model 2. In model 3, CFT scores were not a significant predictor of fear of dementia score at time 2. (F=.325, df1=1 df2=331 p=.569).

At the level of individual variables, there were significant effects throughout all three models for age (t= -2.11, b= -.106 p=.036), family history (t =3.540, b=.179, p=.000) and total subjective cognitive complaints (t= 6.280, b= .316, p=.000). A full depiction of the findings from the regression analysis can be found in table 6.

Table 6

Regression analysis for FOD at follow up

Variable	B (SE)	Standardised β	t	p	R2 change
Dependent variable FOD2 (N=338)					
Model 1					0.65
Age at testing	-.338(.15)	-0.119	-2.251	0.025	
Fam history of AD	5.26(1.26)	0.221	4.175	0	
Model 2					0.121
Age at testing	-.29 (.14)	-0.102	-2.061	0.04	
Fam history of AD	4.34 (1.19)	0.182	3.639	0	
SCC1	2.48 (.39)	0.316	6.31	0	
GAD71	-.063 (15)	-0.025	-0.434	0.665	
FOD1	.137 (.06)	0.138	2.437	0.015	
Model 3					0.001
Age at testing	-.304 (.14)	-0.107	-2.12	0.035	
Fam history of AD	4.261(1.2)	0.179	3.54	0	

SCC1	2.474 (.39)	0.315	6.292	0
GAD71	-.064 (.15)	-0.025	-0.44	0.66
FOD1	.137(.06)	0.138	2.434	0.015
CFT score	-.029 (.05)	-0.029	-0.57	0.569

Discussion

Interpretation of findings

This project aimed to establish whether engaging in an online screening for mild cognitive impairment had an impact on fear of dementia, and to identify potential predictors of fear of dementia. The data revealed an interaction between the type category of feedback participants received from the Cognitive Function Test (CFT), and Fear of Dementia scores over time. Friedman's test identified significant effects for CFT category on the differences of FOD, SCC and GAD7 scores.

This project identified that the category of feedback on CFT interacts with the change in scores on FOD, SCC and GAD7 between time 1 and time 2 with a moderate level effect for the variance across the different variables. The largest effect identified appeared to be the impact of the 'amber' feedback category on FOD at follow up with FOD decreasing.

This project also had the view to explore whether fear of dementia is influenced by feedback on one's cognitive functioning as measured and reported by the Cognitive Function Test, while controlling for factors such as anxiety, subjective cognitive concerns, demographic variables and family history of dementia. Through hierarchical regression this project identified that fear of dementia at follow up is predicted by lower age of participants, degree of subjective cognitive concern and having a family history of dementia.

This research did not identify a predictive effect of scores from the cognitive function test on subsequent fear of dementia scores at time 2. This was in spite of significant change on fear of dementia scores between conditions at time 1 and time 2. Another reason for a lack of effect of CFT scores on subsequent fear of dementia scores may be a consequence of the statistically insignificant relationship between CFT scores and FOD scores. Exploration of Beta coefficients within the regression analysis revealed that the coefficients for CFT scores were much weaker than for subjective cognitive complaints and family history. CFT scores also present an objective measure of complaints, whereas FOD scores are a measure of subjective concern, which may also explain some of the discrepancy.

Comparison to available literature

Some of the findings within this project echo results available within the literature. Among the correlations within this project, there was a significant relationship between anxiety symtpoms on the GAD7 and total subjective cognitive complaints. As identified within the literature review of this thesis, as well as in Delphin-coombe et al (2016)'s study of participants presenting at memory clinics, anxiety is associated with memory concerns at baseline. Tang and colleagues (Tang, Kannaley, Friedman, Edwards, Wilcox, Levkoff et al, 2017) identified how indiviuals are more likely to self select for screening if they notice cognitive changes. Surprisingly, among this sample of self-selecting individuals, the total mean score for subjective cognitive concerns was less than half the total possible score. However, the accrued mean score may not be the most reflective measure and endorsing at least one complaint may be more indicative, particularly as subjective cognitive concerns were the strongest among all the predictors for fear of dementia at time 2.

In an analysis of data from the Michigan health and retirement survey, Cutler (2015), compared worry over different illness with concerns regarding memory decline and proximity to dementia. Similar to the findings from the primary analysis within this project, Cutler identified that familiarity with dementia yielded an effect on fear of dementia. The role of family members having dementia is similar to the findings by Jeong et al (2016) regarding caregiver's experiences and subsequent fear of dementia. Similar findings were also identified by Tang and colleagues (2017) who identified that family members of people with dementia had higher levels of concern about developing dementia than non-family members.

Age at the time of testing was found to be a significant predictor of fear of dementia, however,participants of younger age, within a sample of 50-65 year olds, appeared to more strongly predict fear of dementia. This is supported by findings in Cutler & Bragaru (2015) and Roberts et al (2014, as cited in Tang et al 2017), who identified participants of increasing age to be less worried about developing dementia.

At baseline, anxiety was a significant predictive factor for fear of dementia, with fear of dementia and general anxiety scores having a moderate relationship. Anxiety among older adults and individuals with dementia has been associated with poorer quality of life, higher rates of problematic behaviours and increased risk of requiring residential care (Seignurel, Kunik, Snow, Wilson & Stanley, 2008). In a recent analysis regarding individual's beliefs about dementia, Quinn and colleagues (Quinn, Morris & Clare 2018), identified how specific beliefs impacted how an individual felt about dementia. Within this project, anxiety predicted fear of dementia prior to receiving feedback on the CFT. After receiving information about this at time 2, however, anxiety was not considered to be

predictive of fear of dementia. While there were no significant predictive effects for anxiety on fear of dementia at follow up, the role of anxiety on selection for screening and its potential effects on individuals over time requires further attention. Qazi et al (Qazi, Spector & Orrell 2010) identified the importance of practical and emotional support around the time of diagnosis, and findings from the literature review component identified the importance of proper assessment and appropriate intervention at the point of presentation with cogntive concerns. Anxiety, whether as an adjunct to or separate from fear of dementia, appears to play a role in identifying and repsonding to early dementia symptoms.

The demographics within this study also resemble findings within similar research projects. Tang and colleagues identified a discrepancy among gender rates and worry about dementia, reporting women to be more concerned overall than men (2017). Within this sample of self-selecting participants, almost 80% of the sample were women. One might hypothesise that women within the general population are more engaged in help seeking and screening for conditions such as mild cognitive impairment.

Clinical and policy implications

This project presents a number of potential ideas for clinical practice and implications for public health policy. This project provides some insight into how participants within a help-seeking population respond to feedback on their cognitive health and advice for preventing potential cognitive decline. It is considered of interest to also consider how this information may inform policy and the scope of health behaviour practices at a population level.

Within this study, the findings indicate that feedback identifying participants 'at risk' for cognitive decline increased fears and worries in relation to developing dementia, while

participants identified within ‘green’ or ‘amber’ categories, indicative of lesser risk, were reassured by their scores. Feedback was also partnered with recommedations with lifestyle changes understood to potentially improve cognitive health. The recommendations are in line with the dementia prevention and intervention guidance (Livingston et al., 2017; Department of Health, 2018). The role of early screening and individual health behaviour change form part of the complex picture of individual health and population-level risks. This may be encapsualted as part of the ‘paradox of prevention’ (Rose, 1992; as cited in Broadbent 2011), which outlines that ‘risk’ as presented by epidemiologists is not synonymous with indivdual risk. Recommendations to prevent population-level risks may not serve to reduce a specific indivdiual’s risk. Policy aimed at prevention and early identification, including prompts relating to potential dementia symptoms for over 65s at health checks, may also serve to increase individual fear.

Kessler and coleagues (2012) identified that increased fear of dementia may result in more negative attidues towards ageing and result in hypervigilance of symptoms. The theoretical domains framework behind Michie’s behaviour change wheel (Michie et al 2011; Cane, O’Connor & Michie 2012) identify how the behaviour change model can be mapped onto a number of different domains. Among these are domains related to optimism, belief about consequences and emotion. Subjective cognitive concerns and its predictive effect on fear of dementia may play a role in identifying targeted areas for intervention to increase the uptake of health behaviours. Clinically, when considering the potentially limiting role of fear of dementia when presented with concerns within primary concerns for example, itt would be important to balance this with realistic reassurance to better support individual well-being.

This research identified how, even following feedback regarding one's current cognitive functioning and recommendations for changes, having a family history of dementia remained a significant predictor for ongoing fear of dementia. It would be reasonable to prioritise those with a family history of dementia for interventions looking. One such intervention may be having a family briefing session at the time of dementia diagnosis, allowing family members to ask questions and gather information they might find helpful and to dispell any potential myths which might arise. Another intervention might be for general practitioners to monitor and consider a referral for individual psychological support for individuals with increased anxiety in relation to developing dementia or subjective cognitive complaints among individuals with a family history of dementia. This complements the London dementia clinical network (2018)'s recommendations for adults who do not have dementia.

Subjective cognitive concerns were a significant predictor of fear of dementia and were also correlated with anxiety at baseline. As identified in the literature review of this dissertation, subjective cogntive concerns have been found to be a significant risk factor for the development of dementia even when controlling for common mental health difficulties. Subjective cognitive concerns here appear to also play a role in screening among the general population and individuals are thought to be more likely to seek help if they are aware of cognitive changes (Tang et al 2017). Increasing awareness of potential cognitive changes, including those which may not be memory related, and enabling screening for potential objective impairment to occur alongside a more thorough assessment of common mental health presentations and other modifiable lifestyle factors which may address potential disability caused by dementia over time.

~~The theoretical domains framework behind Michie's behaviour change wheel (Michie et al 2011; Cane, O'Connor & Michie 2012) identify how the behaviour change model can be mapped onto a number of different domains. It is thought among Cane and colleagues, who reviewed the framework, that the refined domains framework could inform the implementation of behaviour change interventions. Among these are domains related to optimism, belief about consequences and emotion. Subjective cognitive concerns and its predictive effect on fear of dementia may play a role in identifying targeted areas for intervention. The specific category of feedback on the CFT may also have implications for responses to feedback on behaviour change, when considering the interaction effect of CFT on FOD scores over time.~~

Despite the final sample size within this project being relatively modest, the initial response to recruitment and uptake of the cognitive function test was rather large, with almost five thousand individuals registering interest on the UCL information, consent and data collection platform. This helps identify the potential of electronic and web-based interventions, even among a demographic which may have been traditionally less accustomed to computer-based interventions.

Limitations

There are factors which act as limitations to this project. Friedman's ANOVA was chosen as a non-parametric equivalent to repeated measures ANOVA in light of the data violating assumptions of normality. There is reasoning within the statistical literature that the Friedman test is not a direct equivalent for the repeated measures ANOVA (Baguely, 2012), recommending, instead, rank transformation of data to enable parametric equivalents.

Time limitations meant that it was not possible to run transformation on the required data, having implications for the sensitivity of the analysis within this project.

This research also initially aimed to identify the predictive effect of proximity to dementia on fear of dementia. However, specific questions on the nature of proximity; such as that which might have arisen out of a paid caring role, media exposure or direct family member living with dementia, were not included as part of data collection as it was thought they were included on the other data collection platform. Family history of dementia was thus used as a the sole indicator for proximity to dementia, potentially overlooking the different levels of proximity which individuals within the general population may encounter.

This sample consists of mostly female, White British participants who were already self-motivated to procure resources related to health behaviour, which is not representative of the general population. Interventions and research on preventative health behaviours appear to often overlook individuals from marginalised communities (Tang et al 2017). When exploring potential confounds for fear of dementia, this project considered the potential impact of general anxiety symptoms and aimed to assess this using the GAD7 scale. This project, however, failed to incorporate a measure of depression symptoms which may act as a confounding variable given the high rates of comorbidity between depression and anxiety symptoms (Kessler, Merikas & Wang 2007; as cited in Zhou 2017). The psychometric properties of fear of dementia scale used within analysis are yet untested, which may limit the rigour of the study.

Areas for future research

This project has been able to corroborate findings on what influences fear of dementia among adults below the age of 65 in the general population. To inform further

understanding about the influence of fear of dementia on undertaking proactive cogntive health behaviour changes, additional research may be helpful. This project has presented the impact of cogntive function test results on fear of dementia immediately after receiving one's results. It would be of interest to explore what the effect of such feedback is at longer-term follow up, and whether the relative fear of dementia at follow up has an impact on the uptake of recommended health behaviour practices.

Another area for further exploration is dementia stigma. This has been identified on both an interpersonal level (Hughes et. al, 2017; Riley, Burgemer &Buckwater, 2014) as well as on an individual level (Tang et al 2017). It would be of interest to consider whether fear of dementia and dementia stigma may influence the effectiveness of health behaviour awareness campaigns, or engagement with cognitive health behaviours, as well as the interaction between the two phenomena.

The demographics of the participants within this study were predominantly female and White British. Anderson and colleagues (Anderson, Day, Bear, Reed & Wu, 2009) identified gaps within the literature for participants from minority ethnic backgrounds. It would be interesting and useful for future research to address perceptions regarding dementia and preventative health behaviours across different social and cultural groups to inform interventions which may be applicable to a wider reach within society.

Conclusion

Fear of dementia is a construct which appears to contribute to self-selection for screening for mild cogntive impairment. This study identified that FOD is correlated with general anxiety symptoms as well as subjective cognitive cognitive complaints. FOD is predicted by these factors as well as participant age and family history of dementia. Analysis of variance identified that FOD scores appear to change in response to the category

of feedback participants received on the CFT, with scores in the amber category having the largest effect. The findings in this project have implications for identifying priority populations to target preventative health behaviours to maximise their uptake at a public health level and to consider interventions for anxiety difficulties at the point of screening. Areas for future research include considering the impact of FOD on long-term response to feedback on screening and the interaction between uptake of behaviours and FOD and general anxiety symptoms.

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Part 3: Critical Appraisal

Introduction

This dissertation provided me the opportunity to consider help-seeking in relation to screening for cognitive impairment as well as how mental health difficulties, particularly anxiety may be implicated in the development of dementia. I have been able to engage with different methods of data collection and integrating information and undertaking the research has encouraged me to think about the varied contributions of clinical psychology research and the translation of research findings to policy and practice.

This appraisal will be formed of three parts, the first reviewing the choices made regarding the methodology of this research project; the second involving a critical reflection of the contribution of Clinical Psychology research to public health; the third and final involves a reflection on the research process and how this has informed my professional development as a Clinical Psychologist.

Part 1: Methodological choices

This project required me to make a few methodological choices. Michie's model of behaviour change (Michie, Stralen & West 2011) provided sufficient understanding to consider the influence of affective factors such as fear of dementia on the effect of screening for mild cognitive impairment and subsequent uptake of cognitive health behaviours. Making use of selected items from a measure such as the Fear of Dementia Scale (French, Floyd, Wilkins & Ostato, 2012) enabled a focus on specific constructs which are thought to capture fear of dementia. The specific items asked about sources of concern such as coming

across news stories related to dementia, anxious responses to memory lapses, fears of aging and fears of dementia and its symptoms.

Considering the 'fear' component within the FOD scale, it was agreed by those of us in the research team that including a measure of general anxiety would also be useful. For this, the GAD7 (Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007) was chosen. ~~The GAD-7 is routinely used in IAPT services within the UK and has adequate sensitivity (83%) and specificity (84%) for the detection of generalised anxiety disorder using a cut-off score of ≥ 8 (Plummer, Manea, Trepel, & McMillan, 2016).~~ This measure asks completers how affected they have felt by their symptoms in the past two weeks. This measure, however, was given to participants at follow up a day after completing it at baseline, which may have compromised its sensitivity to change. Using a measure that is routinely used within UK-based services could allow for a comparison between levels of anxiety among the participant sample and the population sample for the ongoing research of which this project forms part.

The original plan was to include more specific items on proximity to dementia, such experiences as a paid carer or residing with a non-relative with dementia. These were not included in the research due to an error in communication between the various parties involved. I had thought that proximity to dementia questions were among the lifestyle and demographic questions collected on the FFB website. These were not among the routinely collected information when users are completing the CFT, however, as I was not able to speak with the technical representatives on FFB directly, this detail was not double checked and the consequence was that these items were not part of data collection. There also appeared to be limited scope on what could be added to the CFT pages as these were already designed as part of the FFB website.

It was decided, however, that family history of dementia will be used as a proxy measure for this construct. It has been identified in the literature that family history of dementia is associated with increased fear of dementia (Jeung Sun, Eun Ha & Minjeong 2016), however this approach does lend itself to potential confounds, such as participants having exposure to dementia through paid care work, media or community exposure.

The questions which mapped onto subjective cognitive complaints were part of the data collected routinely by the Food for the Brain charity, the research partner for this project. It was noted, however, that the questions asked included questions about specific memory complaints and it also prompted about concerns related to word finding, disorientation and concerns that others share. This is considered to be a more rounded assessment of subjective cognitive complaints, as other assessments in the literature have been criticised for only focusing on memory decline (La Joie, Perrotin, Egret, Pasque, Tomadesso, Mezenge et al 2016; Reisberg et al 2010).

The grouping of scores on the Cognitive Function Test (CFT) by Trustram and De Jager (2014) informed the type of feedback participants received on the test. Although participants received a continuous score, the cut offs for these scores created categorical variables within this project. The continuous scores were grouped into categories; scores within the range of 110-43 were in the 'green' category, scores within the range of 42-38 were in the 'amber' category and scores within the range of 37-0 were in the 'red' category. The ratio between different categories, however, was not equal, with the majority of scores falling in the green category, and only five potential scores falling in the amber category, with the remainder of scores falling in the red category, which is indicative of mild cognitive impairment. This had consequences for the size of the sample in each group, which revealed a large proportion of the sample in the green (86.7%) category. Graphical representation and Friedman's test illustrated an interaction effect, particularly for the amber

category, which lowered scores more than receiving feedback that ones' scores were in the green category. We have hypothesised that participants may be more reassured by the amber category feedback. This has implications for considering the way feedback is delivered, particularly as the score range between amber and red is rather small.

The methodology of this project required a series of decisions to be made which have had an effect on this project as a whole. Some of these, such as not having sensitive or specific proximity to dementia questions and the distribution of participants among the different CFT feedback scores, appear to have an impact on the quality of this project as a whole and the potential to identify meaningful findings. Other aspects, such as using select items from the Fear of Dementia Scale and using a range of questions to assess subject cognitive complaints, better enables this project to understand the nuanced role these phenomena may play in the promotion of cognitive health behaviours.

Part 2: The contribution of Clinical Psychology approaches to public health

Working on this project has afforded the opportunity to consider the contribution Clinical Psychology may offer to public health and how this can inform preventative interventions for modifiable difficulties such as dementia. This section will consider how this project applied Clinical Psychology principles alongside larger behaviour change interventions and how these can be more closely aligned with public health prevention principles. This involved working alongside colleagues in the third sector, which provided different insights into the research process and engaging the general public.

This project has explored the role of common mental health problems and how this may influence cognitive impairment. Within the literature review of this project, it was identified that depression and anxiety significantly effect cognitive complaints and that this

can contribute to cognitive impairment in the form of dementia at follow up. This identified that addressing common mental health difficulties may be one way of reducing the effect of dementia later in life. The empirical portion of this project explored how anxiety and fear of dementia play a role in screening for mild cognitive impairment and the effect of screening results on pre-existing fear of dementia.

Additions to the literature on public health appear to echo a theme of integrating skills to inform multi-level interventions. Davies and colleagues (Davies, Winpenny, Ball, Fowler, Rubin& Nolte 2014) reported that the changing burden of disease is more related to modifiable lifestyle factors and prevention attempts need to address this. The current report incorporates cultural, social, clinical, biomedical and structural responses within society to address this. Exploring the role of fear of dementia in relation to screening, as well as the effect of common mental health difficulties on cognitive impairment, may be considered part of a clinical response to public health prevention and intervention.

Placa and Knight (2014) identify the importance of different levels of interventions. Wilber's integral theory (2001, as cited in Hanlon, Carlisle, Riley, Lyon & Hannah 2010) maintains that human experience is the outcome of multiple interacting factors, including scientific theory, empirical perspectives, collective experience, macro social structures and social policy as well as ethics, and subjective norms. This may complement the idea of diverse levels of interventions such as those identified as potential ways of implementing resources within this research project, both at the point of presenting with cognitive complaints as well as when help seeking through screening. One such example is Qazi and colleagues' (Qazi, Spector & Orrell 2010) qualitative report on the identification and support for anxiety in relation to living with a diagnosis of dementia. Qazi and colleagues identified the importance of anxiety support around the point of diagnosis as a way of minimising further disability as the condition progresses. The type of support identified

included individual support, but also environmental changes and working with individuals in caring roles. By identifying general and specific anxiety difficulties alongside subjective cognitive complaints and screening for mild cognitive impairment, this project points to a number of different levels of interventions which may be implemented to support individuals hoping to identify any specific difficulties in relation to cognitive impairment.

In a survey among participants at the Centre of Excellence, McAaney and colleagues (McAney, Mcann, Prior, Wilde and Kee 2014), aimed to explore ideas about translating research evidence into clinical practice. This project identified differences among the priorities of academics and non-academics, with non-academics valuing the utilisation of knowledge by means of knowledge brokerage and academics prioritising the publication of knowledge generated. McHaney et al (2014) acknowledge the complexities within the evolving systems of the public health sector and maintain that partnership and flexibility will be required to face ongoing challenges that the public sector may face. This project was able to explore whether a new screening intervention can be meaningfully used to offer feedback on cognitive health behaviours, while directly applying behaviour change understanding to adults within the general population using ehealth interventions.

Considering the effect of common mental health difficulties on subjective cognitive complaints, as well as the interaction of fear of dementia and screening for mild cognitive impairments, appears to have implications for the delivery of public health promotion around the role of lifestyle factors and dementia prevention. This project offers an illustration of how Clinical psychology has the potential to offer a unique perspective, requiring an understanding of mental health presentations, human behaviour, as well as the research process and knowledge of service delivery and disseminating information.

This section has considered the contribution Clinical Psychology can offer public health in relation to conducting research and evaluation of public health interventions, to understanding the translation of research into standard practice and to integrate different levels of intervention in support of public health.

Part 3: Professional development

The approach taken within this research project has been a completely new venture for me. The research I had previously undertaken had involved small-scale, experience-led research projects informed largely by qualitative methodological approaches. This project presented opportunities to utilise a different method of data collection, analysis, as well as understanding and implications for dissemination.

Employing analyses such as hierarchical regression provided me with the opportunity to engage with larger-scale data analysis which can be generalizable to the general population. This has enabled me to appreciate the importance of sample power and how this may influence the hypothesised effect. Making use of an online recruitment strategy was also a new approach undertaken for this project, and I was struck by the extent of the reach this method had. For this process, I became familiar with the ethical guidance for internet-mediated research (British Psychological Society, 2013). This required considering the process of sharing information about the project, identifying whether participants met the inclusion criteria and gathering active consent without physically meeting potential participants. Reaching participants and running the experimental component of the project also required collaboration with the charity sector, which was also a new process for me.

Working on this project in collaboration with a charity was a key driver in enabling this project, however, this required me to attend to a number of issues. Working in

collaboration with the third sector afforded the opportunity to engage members of the public. Food for the Brain's (FFB) role as an information and research charity provided a platform for participants to engage with the cognitive function test and personalised lifestyle recommendations to maintain or improve their cognitive health. Collaborating with FFB enabled the information about my specific project, exploring the impact of screening on fear of dementia, to be communicated to thousands of potential participants inviting them to participate in the research project. To enable data to be collected, plans needed to be iterated several times for this to be properly coordinated. As a research team, our priorities involved balancing robust and accessible measurement to allow for some conclusions to be drawn from the collected data. However, it is understandable that a non-academic charity have different priorities and the nuances relating to timing of data collection and specific wording in adverts needed to be communicated sensitively and clearly. This required an amount of project management, coordinating between FFB, the research team and the psychology department to ensure compliance with ethical best practice. This also introduced challenges related to communication about the project and promotion using the brand of an institution such as UCL. This required cautious communication and it was agreed that one member of the research team would act as a 'link' person between the research team and the recruiting charity to ensure one clear channel of communication.

Indirect recruitment required further consideration and resulted in a few unexpected consequences. One instance involved the fact that certain demographic information, namely marital status and years of education, were no longer collected through the charity website, resulting in large quantities of 'null' data being returned. The requirements for data collection at time 2 were also misunderstood, with participants receiving an email after 24 hours rather than immediately after getting feedback on the CFT as initially conceived within the research design. Participants were also directed to complete the entire cognitive

function test once again, resulting in unnecessary demands on participants and potentially resulting in increased drop-off in participants at time 2. Recruitment and data collection required repeated communication as this also involved liaison with website developer colleagues, and data needed extensive cleaning, recoding and merging as many extraneous variables and null data was included among the required data. The challenges of indirect design within internet mediated research was identified as one of the unique characteristics of this kind of research by the British Psychological Society (2013), reflecting on how the limited level of control may influence the overall scientific value of the research.

However, the reach of the website and the participant uptake of research over a short space of time, even among a demographic which is traditionally considered less-familiar with electronic technology, highlights the potential for ehealth interventions to engage members of the public.

This project thus required me to flex my approach in terms of the methodology used, as well as the professional approach taken to enable this project to be delivered. The influence of common mental health difficulties such as depression and anxiety have been highlighted as a consequence of this project. This has been identified through the literature review as well as through the empirical component of this project. The literature review identified the importance of attending to common mental health difficulties when individuals might have concerns about their specific memory function.

This project has also encouraged me to reflect on my own assumptions relating to dementia and prevention. At the beginning of this project, I, like many others (Alzheimer's Society, 2017) viewed dementia as a largely organic process which was predetermined. This project has enabled me to understand the role of modifiable lifestyle factors, and how this can help ameliorate the risk of dementia in later life.

Appropriate assessment and intervention for these presenting difficulties may address cognitive impairment and complaints. Engagement with screening and the role anxiety and specific fear of dementia may have on responding to feedback was identified in the empirical paper within this project.

The varied experiences and learning opportunities afforded through this project emphasised the importance of being flexible in my approach, responding to challenges as they arise and making attempts to prevent these and I have also reflected on the role of common mental health difficulties in promoting cognitive health.

This appraisal has attempted to reflect on the different issues related to measurement and methodology within the project, including the impact of running research alongside a partner organisation. This appraisal has been able to consider the role Clinical Psychology can play within wider public health interventions and the value of the varied skillset that enables this. While it has been a learning curve for me to undertake this project, I have been able to better understand the interplay between subjective cognitive complaints, common mental health difficulties, fear of dementia and preventative health behaviours. Dementia research is considered to be of increasing importance in light of the aging nature of our population and the costs attributed to caring for people disabled by dementia (Alzheimer's Society, 2018). Doing this project has allowed me to contribute to an important area of research and to better understand how my training as a Clinical Psychologist can be applied to address challenges the impact of dementia may represent.

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Appendices

Appendix I-Critical Skills Appraisal Cohort Study Checklist

Section A: Are the results of the study valid?		
1. Did the study address a clearly focused issue?	Yes ☐ Can't Tell ☐ No ☐	HINT: A question can be 'focused' in terms of • the population studied • the risk factors studied • is it clear whether the study tried to detect a beneficial or harmful effect • the outcomes considered
Comments:		
2. Was the cohort recruited in an acceptable way?	Yes ☐ Can't Tell ☐ No ☐	HINT: Look for selection bias which might compromise the generalisability of the findings: • was the cohort representative of a defined population • was there something special about the cohort • was everybody included who should have been
Comments:		
Is it worth continuing?		

CASP
Critical Appraisal Skills Programme

3. Was the exposure accurately measured to minimise bias?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for measurement or classification bias:
- did they use subjective or objective measurements
- do the measurements truly reflect what you want them to (have they been validated)
- were all the subjects classified into exposure groups using the same procedure

Comments:

4. Was the outcome accurately measured to minimise bias?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for measurement or classification bias:
- did they use subjective or objective measurements
- do the measurements truly reflect what you want them to (have they been validated)
- has a reliable system been established for detecting all the cases (for measuring disease occurrence)
- were the measurement methods similar in the different groups
- were the subjects and/or the outcome assessor blinded to exposure (does this matter)

Comments:

CASP
Critical Appraisal Skills Programme

Comments:

Section B: What are the results?

7. What are the results of this study?

HINT: Consider
- what are the bottom line results
- have they reported the rate or the proportion between the exposed/unexposed, the ratio/rate difference
- how strong is the association between exposure and outcome (RR)
- what is the absolute risk reduction (ARR)

Comments:

8. How precise are the results?

HINT:
- look for the range of the confidence intervals, if given

Comments:

CASP
Critical Appraisal Skills Programme

9. Do you believe the results?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- big effect is hard to ignore
- can it be due to bias, chance or confounding
- are the design and methods of this study sufficiently flawed to make the results unreliable
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

Comments:

Section C: Will the results help locally?

10. Can the results be applied to the local population?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- a cohort study was the appropriate method to answer this question
- the subjects covered in this study could be sufficiently different from your population to cause concern
- your local setting is likely to differ much from that of the study
- you can quantify the local benefits and harms

Comments:

11. Do the results of this study fit with other available evidence?

Yes ☐
Can't Tell ☐
No ☐

Comments:

CASP
Critical Appraisal Skills Programme

12. What are the implications of this study for practice?

Yes	
Can't Tell	
No	

HINT: Consider
- one observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- for certain questions, observational studies provide the only evidence
- recommendations from observational studies are always stronger when supported by other evidence

Comments:

CASP
Critical Appraisal Skills Programme

5. (a) Have the authors identified all important confounding factors?

Yes ☐
Can't Tell ☐
No ☐

HINT:
- list the ones you think might be important, and ones the author missed

Comments:

5. (b) Have they taken account of the confounding factors in the design and/or analysis?

Yes ☐
Can't Tell ☐
No ☐

HINT:
- look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

Comments:

6. (a) Was the follow up of subjects complete enough?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- the good or bad effects should have had long enough to reveal themselves
- the persons that are lost to follow-up may have different outcomes than those available for assessment
- in an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort

6. (b) Was the follow up of subjects long enough?

Yes ☐
Can't Tell ☐
No ☐

Appendix II- Copy of the GAD7

Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Add the score for each column	+	+	+	
Total Score *(add your column scores)* =				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

Source: Spitzer RL, Kroenke K, Williams JBW, Lowe B. A brief measure for assessing generalized anxiety disorder. *Arch Inern Med.* 2006;166:1092-1097.

Appendix III- copy of the fear of dementia questions used in this research

Please indicate how much you agree with each of the statements below by selecting one appropriate response

			Never	Rarely	Sometimes	Often	Always
The older I get, the more fearful I become that I may develop dementia.							
I am afraid of losing my memories.							
Even though my memory is good, I am still afraid of developing dementia.							
When I misplace things, I sometimes think that I may have dementia.							
When I hear about others with dementia, I become fearful that I will get it as well.							
I think that I will probably get dementia, and it frightens me.							

Now that dementia is becoming more publicised with the diagnosis of popular TV, movie and political figures, I am becoming more afraid that I may develop it.							
I am afraid of getting dementia.							
Developing dementia frightens me because I would eventually lose all of my independence.							
I fear not recognising family members.							
When I think about the possibility of developing dementia, I become nervous or anxious.							
I worry about developing dementia more							

than I worry about developing other diseases.							

Information Sheet for Participants in Research Studies

Title of Project:

An evaluation of an online supported Cognitive Function Test for cognitive screening and its role for cognitive health promotion.

Investigators:

Glorianne Said, Dr Elisa Aguirre, Dr Georgina Charlesworth

UCL, Gower Street, London, WC1E 7HB +44 (0)20 7679 2000

We would like to invite you to participate in this research project directed by researchers at UCL. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. If you decide to take part in this study, you can still stop at any time without giving a reason. Before you decide if you would like to take part, it is important for you to read the following information carefully.

In this study, we are investigating the effects of completing an Online Cognitive Function Test provided by Food for the Brain website, a not-for-profit charity which provides nutritional and well-being advice in order to promote mental and physical health. We will be asking you to complete a questionnaire in order to assess the effects that the test can have in terms of behaviour change and psychological outcomes including anxiety and dementia worry. In total, the survey should take about 20 minutes to complete. You will be directed back to the Cognitive Function Test link afterwards. This test consists of four parts and it will take approximately 15 minutes to complete.

In order to thank you for your time and participation in this study, you will have the chance to be entered into a prize draw for £100 in vouchers for a retailer of the winner's choice.

All data will be handled according to the Data Protection Act 1998 which means that the personal information that you give for this survey will only be used for the purposes of the survey and will not be transferred to an organisation outside of UCL. All data will be kept confidential and anonymous. Only members of the research team will be able to access this information. In discussing the study's results we will not name any participants, or publish anything that could leave any participant identifiable.

This study has been approved by UCL Clinical, Educational and Health Psychology Department's Ethics Committee.

[Project ID No]: XXXXX

Appendix V Confirmation of ethical approval

KJ

King, John

Reply all

Tue 26/09/2017, 11:20

Aguirre Elisa <Elisa.Aguirre@nelft.nhs.uk>;

Said, Glorianne;

+3 more

Inbox

CEHP2017_563_Charlesworth2017.zip

909 KB

Show all 1 attachments (909 KB) Download

Save to OneDrive - University College London

Dear Georgina and Elisa,

I am writing to let you know that we have approved your ethics application, "Attitudes towards cognitive health and behaviour change related to an online supported Cognitive Function Test and lifestyle recommendations." Thank you for taking such care to follow up my concerns about reputational risk in relation to the project.

The approval reference number is CEHP/2017/563. I have attached a copy of your application form.

I will keep the approved forms on file, and a copy has been lodged with the UCL Research Ethics Committee (cc'd herein). Please notify us of any amendments, in line with guidance on the PaLS Intranet.

Best Wishes,

John King

Chair of Ethics, CEHP

--

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