



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) A systematic scoping review of the role of death anxiety in obsessive-compulsive disorder; 2) An evaluation of group STrAtegies for RelaTives (START) for carers of people with dementia; 3) An exploratory study on the relationship between death and care attitudes in professionals working in dementia care.

Kwapong, Ben

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

Benjamin Kwapong

Doctorate in Clinical Psychology

University of Bath
Department of Psychology

June 2023

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Statement of impact: Covid-19 Pandemic

The Covid-19 pandemic mostly impacted my research portfolio by negatively impacting my psychosocial well-being whilst on the course. Research ideas and protocols were developed in the first year of training and this period was difficult because I had to juggle managing the uncertainty and distress arising from the pandemic with new demands from the course. Having relocated to a new area, with no known contacts, I found it difficult to settle, which in hindsight impacted my performance levels.

The advice given in the first year was to complete the service-related project (SRP) as part of the first placement. However, the services hosting my first two placements were not in the position to prioritise engaging in research or audits (as a result of covid-19) and hence I was not able to complete the SRP here. Fortunately, I was able to contact other services that had research readily available. Even with this, there were delays in commencing the research as acute service priorities had changed and there were problems in locating vital documents needed for the SRP to progress.

The scale of my main research project (MRP) was also impacted by covid-19. I was advised to keep it feasible in the context of the pandemic and to focus on a study that could be done online, without a compromise on participant numbers. Additionally, delays with other projects had a knock-on effect on the MRP. At times, the pace of my MRP was also affected especially as a result of multiple, prolonged respiratory illnesses which contributed to narrowing the scope of the recruitment e.g., not having time to recruit via care homes. Fortunately, though, I was able to reach my recruitment target.

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Abstracts

Literature Review: A systematic scoping review of the role of death anxiety in obsessive-compulsive disorder

Background: There are suggestions that some human behaviours are attempts to cope with death anxiety (DA). Whilst there are adaptive ways of coping, behaviours observed in mental health difficulties, such as in anxiety disorders, are thought to represent maladaptive attempts. There is evidence that the DA may underlie a range of anxiety disorders, which may have implications for treatment. However, the evidence base is limited for the role of DA in obsessive-compulsive disorder (OCD). This paper is a systematic scoping review aiming to 'map out' the evidence base for DA in OCD.

Method: This paper uses the five-stage scoping review method (Arksey & O'Malley, 2005) to guide a comprehensive literature search on PsychInfo, Scopus, PubMed, and Web of Science. The identified studies were screened by title, abstract, and main text. Articles meeting the inclusion and exclusion criteria were selected for review, and the results were presented under the relevant sub-headings.

Results: Of the 1,844 identified articles, nine articles (with 11 studies) were included in the review. There were a mix of experimental and correlational studies. Correlational studies consistently found that DA was associated with OCD severity, development, subtypes, and associated psychopathology. Experimental studies found that reminders of death increased OCD-like tendencies, although this was limited to students and hand-washing OCD. Study quality was variable, with experimental studies performing more poorly.

Conclusion: There is consistent evidence that DA may be associated with OCD. However, further research is needed to increase the quality and confidence in the evidence and to uncover the mechanisms of this relationship. Nonetheless, current findings suggest that DA may be relevant in the clinical treatment of OCD, and this also merits further investigation.

Keywords: Death anxiety, thanatophobia, OCD, mortality salience, fear of death, terror management

Service-Related Project: An evaluation of adapted, group STRategies for Relatives (START) for carers of people with dementia

Informal caregivers play an important role in supporting people living with dementia, but the stress of caregiving places them at an increased risk of mental health conditions. STRategies for Relatives (START) is an intervention that aims to reduce depression and anxiety, but its delivery in group format has not been evaluated. This evaluation examines

outcomes from a START group intervention that was delivered to caregivers as part of routine NHS service. Six participants in the start group intervention completed weekly measures for anxiety and depression. From this, four participants attended a focus group after the group session. Pre- and post-intervention outcomes were evaluated descriptively, and qualitative data were analysed using *reflexive* thematic analysis. Descriptive quantitative analysis revealed variable changes from pre- and post-intervention for each participant, though mean scores shifted from “moderate” to “mild” for depression, whilst mean scores for anxiety remained at “mild”. Qualitative analysis revealed three themes: “value of being in a group”, “impact of group START” and “(lack of) challenges and recommendations.” There is some evidence that group START may be acceptable, clinically useful, and feasible in an NHS context. However, better-powered outcome evaluation would strengthen the rationale for the use of group START in NHS settings.

Keywords: Qualitative, evaluation, dementia, caregivers, START programme

Main Research Project: An exploratory study on the relationship between death and care attitudes in professionals working in dementia care

Death anxiety (DA) – the fear of death, mortality, and the dying process – has been associated with a range of attitudes and behaviours in healthcare professionals. Although DA may impact person-centred care, the recommended approach in dementia care, this relationship has not been investigated. Moreover, the relationship between DA with end-of-life discussion and planning, another important component of dementia care, has also not been explored. The current study used a cross-sectional, correlational design to examine the relationship between DA, person-centred care, and attitudes related to communicating about death. It also explored the role of experiential avoidance. 107 healthcare professionals working in dementia care completed questionnaires online exploring the study variables. Results revealed that DA was positively associated with greater apprehension about talking about death and that a tendency towards avoidance was negatively associated with person-centred care. These findings suggest that DA could play a role in end-of-life discussions for dementia professionals and that the tendency to employ avoidance should be highlighted when considering training in person-centred care.

Keywords: Death anxiety, person-centred care, end-of-life, mortality salience, terror management, dementia

A systematic scoping review of the role of death anxiety in obsessive-compulsive disorder

Benjamin Kwapong

Trainee Clinical Psychology (University of Bath)

bk513@bath.ac.uk

Literature Review

June 2023

Internal supervisor: Dr Ashley Vanstone

External/field supervisor: Dr Anna Strudwick

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Proposed Journal: Journal of Obsessive-Compulsive and related disorders. (Word limit: not specified)

Rationale: This is a quality journal which welcomes clinically oriented reviews on OCD and related conditions. This journal has an international reach and a wide readership beyond clinical psychology.

1. Introduction

Death anxiety (DA), also termed *thanatophobia*, can be described as the fear of the death and dying of the self, others, and afterlife (Lehto & Stein, 2009). The feeling of angst in relation to death has been argued to be an essence of being human, contributing to survival (Becker, 1973). Because mortality is inevitable, it has been a topic of conversation in literature and philosophy since antiquity, and it remains so in modern texts (Breitbart, 2017; Crusalis, 2014; Solomon et al., 2015; Yalom, 2008). At least in the Western world, the anxiety aroused by death may be observed in the use of euphemisms to describe death and dying, such as “passing away” (Menzies & Veale, 2022).

The field of Experimental Existential Psychology argues that awareness of the inevitability of death and the accompanying anxiety are at the root of many psychological problems observed in clinical settings, and that fear of death is one of, if not the primary, motivations underlying human behaviour (Iverach et al., 2014; Yalom, 1989, 2008). In the last 40 years, Terror Management Theory (Greenberg et al., 1986; TMT) has been the lens through which DA and its influence on human behaviour has been explored. TMT researchers appreciate the universality of the fear of death and sought to highlight its role in understanding human behaviour (Pyszczynski et al., 2015). Inspired by the work of Ernest Becker (Becker, 1973), the premises of TMT are that human beings possess a drive to survive but also a unique capacity to be aware of their mortality, an awareness that has potential to cause terror (Arndt et al., 2005; Pyszczynski et al., 2015). This terror can impede functioning if not managed.

According to the dual-process model of TMT, management of anxiety depends on whether the awareness of death is in the conscious or unconscious (Pyszczynski et al., 1999). When the reality of death is conscious, people engage in ‘proximal’ defences, which is characterised by attempts to remove reminders of death from the conscious mind or deny mortality. ‘Distal’ defences in response to the awareness of death occur at an unconscious level (Pyszczynski et al., 1999). Here, people are thought to think and behave in ways that are in accordance with cultural worldviews which are a set of standards, values, and ideas that, if adhered to, could offer a buffer against DA by providing a sense of symbolic or literal immortality (Burke et al., 2010). According to TMT, self-esteem emerges from how well one is adhering to cultural worldviews. Hence, high self-esteem can also be a DA buffer (Pyszczynski et al., 2015). There is evidence that increasing self-esteem acts as a buffer for DA and reduces accessibility of death thoughts (Greenberg et al., 1993; Hayes et al., 2010; Hayes et al., 2008).

The mortality salience (MS) hypothesis claims that people increase their reliance on distal defences – such as adhering to cultural worldviews – when the reality of death is made salient (Pyszczynski et al., 2015). A large number of studies have provided support for this hypothesis. In these studies, which are typically experimental, mortality salience is

achieved by asking participants in the experimental condition to answer two open-ended questions about thoughts and emotions which may arise when thinking about their own death and what they think will happen to them as they physically die (Rosenblatt et al., 1989) whilst those in a control condition respond to open-ended questions about dental pain. A meta-analysis of 277 studies found that MS had a combined moderate effect size of $r^2 = 0.35$ (Burke et al., 2010). There have been over 1,500 studies looking at the effect of MS (Chen et al., 2022), and the evidence include findings that increasing MS leads to more favour towards one's ingroup (Castano et al., 2002), increased desire for children (Wisman & Goldenberg, 2005) and fame (Greenberg et al., 2010), supporting the idea that humans try to assuage DA by trying to achieve symbolic or literal immortality. Despite some more recent failures to replicate the effects of MS (Klein et al., 2022; Sætrevik & Sjøstad, 2022; Schindler et al., 2021), the volume of evidence is in favour of MS and it offers an explanation for the desire to achieve, belong, and strive for self-esteem but also as the motive underpinning 'undesirable' human behaviour such as ageism, discrimination and racism and war (Pyszczynski et al., 2020; Pyszczynski et al., 2015).

Becker (1973) argued that one of the consequences of attempts to deny death is the development of mental health problems. TMT, in line with this, has been extended to understanding mental health difficulties. Iverach and colleagues (2014) have argued that not all cope with the fear of death as described above and that some people rely on maladaptive ways of coping, which may indeed be "terror mismanagement". From a TMT perspective, "symptoms" of psychopathology are understood to be attempts to cope with the fear of death in light of an inadequate anxiety buffering system (Arndt et al., 2005; Maxfield et al., 2014). There are clear conceptual or thematic links between the fear of death and mental health disorders. For example, depressive disorders are often linked with existential despair and a preoccupation with death (Arndt et al., 2005; Zuccala & Menzies, 2022). However, the thematic associations between the fear of death and mental health are arguably most strongly observed in anxiety disorders, such as health anxiety disorders, where there are often preoccupations with a potentially fatal medical condition (Iverach et al., 2014; Zuccala & Menzies, 2022). Obsessive Compulsive Disorder (OCD) also has clear thematic links with the fear or prevention of death. Many of the subtypes of OCD (McKay et al., 2004; Sookman et al., 2005), such as checking and handwashing, are associated with the prevention of danger, which may often lead to death (Menzies et al., 2015).

The terror management health model (Arndt & Goldenberg, 2017) may further offer an explanation for the links between DA and anxiety disorders such as OCD. The model asserts that people respond differently to health-related threats depending on conscious awareness. When threats are conscious, people are motivated to reduce vulnerability to death. Applied to OCD, one may respond to threats – such as contact with

a potential contaminant – by reducing vulnerability, for example, through hand washing. The centrality of threat in the model means it may explain why people are motivated to respond compulsively to other forms of obsessions not directly related to a health-related threat. For instance, in OCD where checking is the compulsion, people may be responding to the threat of either themselves or their loved one being harmed. Moreover, the higher incidence of trauma in people with OCD – which may include experiences that are threats to life, and sexual, emotional and physical abuse (Dykshoorn, 2014) – may further explain the link between DA and OCD. Trauma may increase one’s sense of vulnerability to harm and death, and in relation to OCD, an increased tendency to manage threats through control (Destrée et al., 2021).

A number of reviews present empirical evidence supporting the role of DA in anxiety disorders (Dar-Nimrod, 2022; Iverach et al., 2014; Menzies & Menzies, 2023; Zuccala & Menzies, 2022). They include studies demonstrating a correlation between the fear of death and the severity of anxiety disorders and studies suggesting that using existential therapy is effective in reducing symptoms. These reviews conclude that DA may be a transdiagnostic factor, which could account for patients who reappear to services with a different disorder to the one that is successfully treated. These claims, if true, have implications for the treatment of anxiety disorders. However, the evidence in the reviews cited was limited and selected non-systematically, which may potentially bias the evidence base. The current paper aims to systematically review the empirical evidence investigating DA and OCD. Specifically, it adopts the systematic scoping review method, which aims to ‘map’ the current state of the evidence base.

2. Method

The review was guided by the five-stage scoping review process (see Table 1.1 for more information; Arksey & O’Malley, 2005) and the reporting was in accordance with PRISMA Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). An unpublished protocol was developed in partial fulfilment of requirements for the first author’s Doctorate in Clinical Psychology.

2.1 Identifying the research question

For the purposes of this review, the following question was formulated: “What are the scope and characteristics of the empirical evidence supporting the role of DA in OCD?” Specifically, this review aimed to address the following sub-questions:

- What subtypes of OCD are being investigated?
- How are OCD and DA measured?
- What are the study designs?
- What are the main outcomes of the research?
- What is the quality of the studies?

- What are the limitations and gaps in the literature?

2.2 Identifying relevant studies

The literature search procedure was undertaken primarily by the main author. The search was conducted on the following databases: PsychInfo, Scopus, PubMed, and Web of Science Core Collection. Key words were identified through background reading in related research areas, and in consultation with subject matter experts and a specialist research librarian. The following generic search terms were used: “fear of death” OR “fear of dying” OR thanatophob* OR “attitudes to death” OR “attitudes towards dying” OR “attitudes toward dying” OR “existential fear” OR “existentialist fear” OR “death anx*” OR “death fear” OR “mortality salien*” AND “obsessive compulsive disorder*” OR “OCD” OR compuls*. These terms were adapted for each database (see appendix A material for search terms and strategy for each database). This search identified studies that were published up until July 7, 2022. Other means of identifying relevant studies included looking at the citations and references of included studies (on Scopus and Science Direct), searching the TMT website (<https://tmt.missouri.edu/publications.html#B>) and the Iverach and colleagues’ review paper (Iverach et al., 2014). There were no limitations on time frame except that imposed by individual databases.

2.3. Study selection

Studies were included if they investigated DA and/or MS in a clinical population diagnosed with OCD or a subtype of OCD on a validated measure, including those with a co-morbidity, or a non-clinical population whose OCD symptoms were assessed using validated measure. Only empirical studies were included, although primary investigations could be qualitative or quantitative. Studies also had to be available in English and published in a peer reviewed journal. Studies were excluded if they focused on other anxiety disorders, were not published in English or without translation, or if they were conference abstracts or doctoral thesis or opinion pieces, editorials, conceptual papers, or reviews. The entire review process was done with the Covidence software (www.covidence.org). The main author screened the title and abstracts using the inclusion and exclusion criteria. The main author and a research assistant then read the full text of identified articles to see if they met the criteria. Initial agreement for inclusion following full text reading was moderate ($\kappa = 0.57$), and discrepancies were resolved via discussion. The main author also screened the title and abstract from the citations and reference list of the included studies. Studies identified from this method were also read by the main author and the research assistant to assess eligibility. The search strategy and study selection process are summarised in Figure 1.1.

Table 1.1*Stages and explanation of the five-stage model (Arksey & O'Malley, 2005)*

Stage	Explanation
Stage 1 – identifying the research question.	Identifying and developing research questions and definitions, starting with wide definitions for key aspects of the review such as population, intervention and outcomes before setting parameters where necessary.
Stage 2 – identifying relevant studies.	Identify relevant primary studies that is relevant to answering the research question. This stage often involves searching different sources and databases.
Stage 3 – study selection	Inclusion and exclusion criteria are used to select relevant studies. Unlike a systematic review, criteria may be devised post-hoc after the researcher is familiar with the evidence.
Stage 4 – data charting	Extracting and summarising information from the primary research evidence. The information is then 'charted' i.e., summarised or grouped together according to themes or key issues.
Stage 5 – collating, summarising, and reporting the results.	The 'charted' information from all identified studies is collated and presented, typically in a narrative account.

2.4. Data charting

A table was created to extract information from the studies (see Appendix B). Key findings relevant to the aims of the review were also noted. The main author and research assistant reviewed all studies and extracted the above data and quality assessment separately. Consensus was reached via discussion. The Quality Assessment with Diverse Studies (QuADS; Harrison et al., 2021) was used to evaluate study quality. The QuADS is an updated and improved version of the Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2012). It has been shown to possess adequate inter-rater reliability (Harrison et al., 2021). The overall QuADS rating is based on 13 criteria, with scores for each criterion ranging from 0 – 3 (see Appendix D). The score for each study is summed up and a percentage is derived from the total available score. The quality of each study was appraised separately by the first author and research assistant, and discrepancies were subsequently resolved through discussion (see Appendix C for quality rating for each study).

3. Results

3.1 Collating, summarising, and reporting

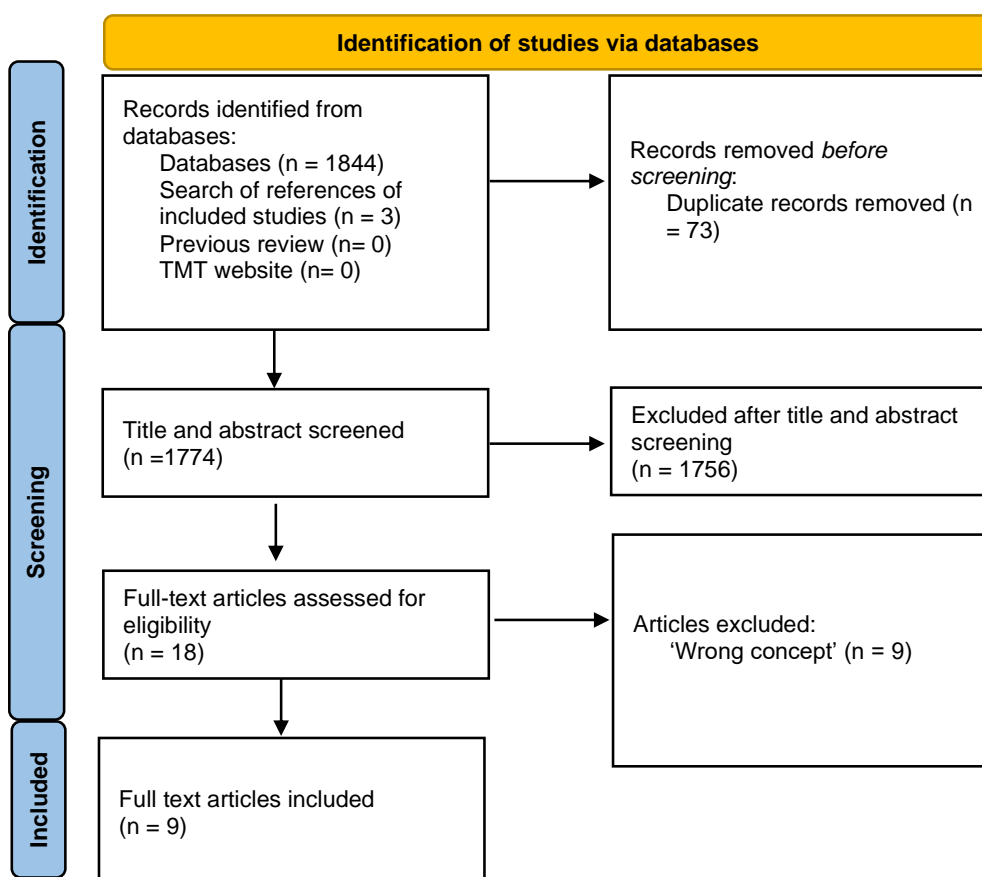
For the purposes of review, the results are organised under the following headings:

- Characteristics of the studies
- Main outcome (s) of the studies
- Quality of the studies

The search of the databases yielded 1,844 records with an additional three studies added from searching the reference list of included studies. With duplicates removed, there were 1,774 records remaining for title and abstract screening. 1,756 articles were excluded following title and abstract screening, leaving 18 studies for full text screening. Nine studies were excluded for investigating concepts other than DA and mortality salience, leaving nine articles in the final selection (see Figure 1.1).

Figure 1.1

PRISMA flowchart of study selection procedure



3.1.1 Characteristics of the studies

Table 1.2 provides a summary of the included studies. There were 11 studies from the nine remaining papers. The papers were published in Australia (73%), USA (18%) and Iran (9%) and were published between 2007 and 2022. 54% of the studies involved participants with a diagnosis of OCD rather than specific OCD subtypes. Three (27%) specifically investigated the handwashing subtype, whilst one study was interested in scrupulosity, and another, in sexual and aggressive obsessions. Four studies (36%) of the eleven were experimental.

The most common measure used to diagnose OCD was the Anxiety and Related Disorders Interview Schedule for DSM-5: Lifetime Version (ADIS-5L; Brown & Barlow, 2014). The Vancouver Obsessive Compulsive Inventory (VOCI; Thordarson et al., 2004) was the most commonly used measure to assess OCD symptoms. Other measures used to capture OCD symptoms included the Maudsley Obsessional Compulsive Inventory (MOCI; Hodgson & Rachman, 1977), the Penn Inventory of Scrupulosity (PIOS; Abramowitz et al., 2002), the Schedule of Compulsions, Obsessions, and Pathological Impulses (SCOPI; Watson & Wu, 2005); the Padua Inventory – Washington State University Revision (PI-WSUR; Burns et al., 1996), and Dimensional Obsessive-Compulsive Scale (DOCS; Abramowitz et al., 2010). The most common measure of DA used in correlational studies was the Multidimensional Fear of Death Scale (MFODS; Hoelter, 1979) which was used in four out of seven studies, followed by the Collett-Lester Fear of Death Scale (CLFD; Collett & Lester, 1969) which was used in two of seven studies and lastly, the Existential Concerns Questionnaire used in one study (ECQ; van Bruggen et al., 2017). All the experimental studies used the MS manipulation (Rosenblatt et al., 1989).

Three of the four experimental samples consisted of students, whereas all the correlational studies involved people with an OCD diagnosis. The sample sizes in the experimental studies ranged from 30 to 132, whereas the sample sizes in the correlational studies ranged from 48 to 200. Almost all the studies included a sample of males and females. Age was captured in seven out of 11 studies (64%) and the most occurring mean age was around 33 years. Where ethnicity was captured (55% of studies), participants were mostly Caucasian followed by Asian. Where patients were participants, comorbidity was reported in five out of eight studies (63%).

3.1.2.1 Experimental Studies

Mortality salience increases OCD behaviours

All experimental studies tested the effects of increasing MS on OCD tendencies in students with compulsive handwashing (CHW) tendencies. Strachan et al., (2007; study

2) using the PI-WSUR to measure handwashing tendencies, divided 46 students into those who had 'high' or 'low' CHW tendencies and randomly allocated them to MS condition or control condition, which required participants to describe what it is like to be excluded by friends. Although they also recorded the number of paper towels used and amount of soap used, the only significant effect was that MS increased the time spent washing in those who scored 'high' in CHW tendencies relative to other conditions. MS did not have a significant effect on those with 'low' CHW tendencies.

Enjedani and Khodapanahi (2011) performed a similar study to Strachan et al. (2007), albeit with the MOCI as the measure for OCD tendencies. They randomly allocated an all-female sample of student participants into the MS condition or the social exclusion control group. The aim of their study also differed as they sought to investigate the role of MS in those with *low* hand-washing tendencies, to see if the effects of MS was applicable in those without 'high' handwashing tendencies. However, they reported that thirty participants scoring in the 'upper' range of the handwashing subscale were selected for the study. Nonetheless, mean time spent washing hands was significantly greater for the MS group compared to the control group.

Fergus and Valentiner (2012) looked at the role of MS in 'mistake checking' behaviour, which is a compulsion related to the scrupulosity subtype of OCD (Greenberg & Huppert, 2010). Students were randomised into standard MS condition or the oft-used dental condition as the control. Following a distraction activity, participants were given a task which involved identifying mistakes in a text. In the MS condition, participants with higher scores of scrupulosity showed significantly more mistake checking behaviour compared to those with lower scores of scrupulosity. This effect was not observed in the dental condition.

Menzies and Dar-Nimrod (2017; study 2) also replicated Strachan et al. (2007) but used 132 participants who were diagnosed with OCD. They used the ADIS-5L and VOI to determine OCD and hand-washing tendencies. Similar to Strachan et al. (2007) they found that MS significantly increased handwashing behaviour – as measured by the amount of soap used and the time spent washing hands – especially for those who had greater tendencies to engage in handwashing as part of their OCD symptoms.

Table 1.2*Summary of included studies*

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
Strachan et al (Study 2) 2007 USA	To examine the effects of death thoughts on compulsive hand washing (CHW) in people with obsessive-compulsive tendencies.	OCD: PI-WSUR MS/DA: MS Manipulation	Quantitative: Experimental	46 psychology students who scored high and low in CHW tendencies. Randomly allocated to MS or control group. 54.3% female. Ethnicity and mean age not reported.	MS significantly increased the amount of time spent washing hands in those with OCD tendencies compared to all other conditions. These effects were not observed for the number of paper towels used or amount of handwashing liquid used.	66%
Enjedani & Khodapanahi 2011 Iran	To test the impact of MS on CHW on students without a high measure of CHW.	OCD: MOCI DA: MS manipulation	Quantitative: Experimental	30 undergraduate students (unclear whether those who scored in the upper scale of washing subscale of the	Mean time spent washing hands was significantly longer following MS compared to the control group.	47%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
				<p>MOCI score or below cut off point of washing subscale was selected).</p> <p>Randomly allocated to MS group or control group.</p> <p>100% female.</p> <p>Ethnicity and mean age not reported.</p>		
Fergus & Valentiner 2012 USA	To investigate whether MS increased mistake-checking behaviours in scrupulous individuals.	<p>OCD: Scrupulosity (PIOS)</p> <p>SCOPI</p> <p>DA: MS manipulation</p>	Quantitative: Experimental	<p>92 students</p> <p>Randomly allocated to MS group or control group.</p> <p>59.8% female.</p> <p>Mean age: 19.7 years (SD = 3.5 years)</p>	MS led to significantly more mistake checking when PIOS scores were high compared to when it was low (partial $r = 0.25$, $p < 0.05$), even when SCOPI was added as a covariate. This effect was not found in the dental condition (partial $r = -0.09$, ns).	83%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
				80.4% Caucasian		
Menzies & Dar-Nimrod (Study 1) 2017 Australia	To investigate the relationship between DA, OCD severity and general psychopathology.	OCD: ADIS-5L (for diagnosis) VOCI DA: CLFD scale	Quantitative: Correlational	171 patients 44% female. Ethnicity and mean age not reported. Co-morbidity not reported.	Moderate to large significant positive correlations between all four CLFD subscales (death of self and others, dying of self and dying of others) and self-reported (VOCI) and clinician-rated (ADIS-5L) OCD severity. CLFD subscale scores were also significantly and positively correlated with clinician-rated and patient-rated measures of lifetime psychopathology.	69%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
Menzies & Dar-Nimrod (Study 2) 2017 Australia	Replicating Strachan et al., (2007). To examine the effects of MS in OCD patients with CHW tendencies.	OCD: ADIS-5L (for diagnosis) VOCI (to determine between 'washers' vs 'non washers') DA: MS manipulation	Quantitative: Experimental	132 participants from study 1. Randomly allocated to MS manipulation or dental condition. 42% female. 58.3% had an additional diagnosis. Mean age and ethnicity not reported.	MS significantly increased time spent washing hands ($\eta^2 = .09$) and soap use ($\eta^2 = .058$) for 'washers' compared to 'non-washers'. This effect was not found for paper towel use.	72%
Menzies et al., 2019 Australia	To examine the association between DA and psychopathology across a range of disorders.	OCD: ADIS-5L (for diagnosis) VOCI	Quantitative: Correlational	200 patients 63% female	Significant and large negative correlation were found between DA and overall composite score for psychopathology for the	91%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
		DA: MFODS		<p>Mean age: 33.76 years (SD = 11.51; range 18 - 65 years)</p> <p>92.5% Caucasian, 6.5% Asian and 0.5% Indigenous Australians.</p> <p>50% had more than one current diagnosis. 79 had OCD.</p>	<p>overall sample ($r = -.79$) as well as the individual components of psychopathology. (Negative scores on MFODS indicates higher DA).</p> <p>There was also a significant, large positive relationship between DA and the severity of symptoms (using a composite score of clinician and patient-rated OCD severity) across anxiety disorders including Generalised Anxiety Disorder, Panic Disorder and Illness Anxiety Disorder and OCD.</p>	

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
Menzies et al., (Study 1) 2020 Australia	To examine whether DA has a relationship with each subtype of OCD.	OCD: ADIS-5L VOCI DA: MFODS	Quantitative: Correlational	79 patients with OCD 36.34% female 91.1% Caucasian Mean age: 33.85 years (range 18 - 65 years) Co-morbidity not reported.	Significant relationship between MFODS and contamination (-.64) checking (-.57), obsessions (-.46), hoarding (-.58), just right (-.58), and indecisiveness (-.62) subscales of VOICI. (Negative scores on MFODS indicates higher DA). Also, there was a significant positive relationship between MFODS and VOICI total score. (-.62).	77%
Menzies et al., (Study 2) 2020 Australia	To replicate study 1 using a larger sample and an alternative measure of DA.	OCD: ADIS-5L VOCI DA:	Quantitative: Correlational	132 patients with OCD 73.92% female. 93.2% Caucasian	There was a significant, positive relationships between 'Death of Self' and 'Death of Others' subscales in all but the contamination subtype.	75%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
		'Death of Self' and 'Death of Others' subscales of CLFD.		Mean age: 33.62 years (range 18 -69 years) Co-morbidity not reported.	There were also significant positive correlations between DA and OCD severity for each subtype. There were no significant differences in the strength of the relationships, except for 'obsessions' subtype, where the correlation between OCD severity and DA was significantly larger compared with the strength of the relationship in the 'contamination' subtype.	
Menzies et al., 2021 Australia	To explore whether DA played a role in the pathway to developing OCD.	OCD: ADIS-5L DA: MFODS	Quantitative: Correlational	98 patients 52% female. 93.8% Caucasian, 6.1% Asian, 1% indigenous Australian.	Those with higher DA were more likely to develop other anxiety disorders <i>before</i> developing OCD. Those with lower levels of DA were more likely	75%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
				<p>Mean age: 33.71 years (SD = 11.54, range 18 - 65).</p> <p>79 (80%) had OCD; 19 previously had OCD but no longer met criteria; 58.2% of the 79 had a co-morbid disorder.</p> <p>Average duration of OCD was 15 years (SD = 11.54 years; range 1 - 53 years)</p>	<p>to have OCD as their first diagnosis.</p> <p>Those with higher DA had significantly more disorders (mean = 2.06, SD = 1.65) before being diagnosed with OCD compared to those with lower levels of DA (mean = 0.24, SD = 0.05).</p>	
Chawla et al., 2022 Australia	To examine the relationship between sexual and aggressive obsessions and existential concerns among individuals with OCD.	<p>OCD: ADIS-5L (for diagnosis)</p> <p>DOCS (to establish eligibility for sexual and aggressive obsessions).</p>	Quantitative: Correlational	<p>48 patients with OCD</p> <p>45.8% female.</p> <p>Mean age: 30.94 (SD = 9.65).</p>	OCD severity significantly and positively correlated with DA (.86), identity (.71), meaninglessness (.45), isolation (.50), guilt (.74) and all relationships remained after controlling for	88%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
		VOCI DA: ECQ (measures DA, meaninglessness, guilt, isolation, and identity).		Co-morbidity: Bulimia (2.1%), GAD (14.6%), Hoarding (2.1%), IAD (6.3%), MDD (21%), Panic (2.1%), PDD (10.4%), Trichotillomania (2.1%) Ethnicity not reported.	neuroticism apart from isolation. OCD severity was also significantly correlated with total ECQ score (.82), above and beyond neuroticism. Sexual obsessions were significantly correlated with identity (.45), isolation (.34) and guilt (.55) even after controlling for neuroticism but was not significantly associated with DA. Aggressive obsessions were positively associated with DA (.65) after controlling for neuroticism, and guilt (.38) but was not significantly associated with identity.	

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
Verin et al., 2022 Australia	To investigate the relationship between DA and OCD and the moderating effect of attachment.	OCD: ADIS-5L VOCI DA: MFODS	Quantitative: Correlational	48 patients with OCD 68.8% female Mean age: 31.2 years (SD = 11.70) 93.8% identified as Caucasian and 6.3% as Asian. 66.7% of sample had additional diagnosis to OCD.	Results revealed that there was higher DA in this population compared to the general population. They also found that higher levels of DA were associated with higher OCD severity, measured by the VOCI ($r = -.72$). (Negative scores on MFODS indicates higher DA). Higher DA scores were associated with greater 'markers' of psychopathology measured by the ADIS-5L: number of medications ($r = -.493$), level of distress ($r = -.449$), number of hospitalisations ($r = -.485$) and severity of	83%

Study Details	Aim(s)	OCD and DA Measure(s)	Design	Sample Characteristics	Main Findings	Quality Assessment Score
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principle diagnosis ($r = -.448$).

Note: OCD – Obsessive Compulsive Disorder, DA – Death Anxiety, MS – Mortality Saliency, PI-WSUR – Padua Inventory-Washington State University Revision, SCUPI - Schedule of Compulsions, Obsessions, and Pathological Impulses, PIOS – Penn Inventory of Scrupulosity, MOCI – Maudsley Obsessional Compulsive Inventory, ADIS-5L – Anxiety and Related Disorders Interview Schedule for DSM-5: Lifetime Version, VOI – Vancouver Obsessive Compulsive Inventory, CLFD – Collett-Lester Fear of Death Scale, ECQ – Existential Concerns Questionnaire, MFODS – Multidimensional Fear of Death Scale, DOCS – Dimensional Obsessive-Compulsive Scale, GAD – Generalised Anxiety Disorder, IAD – Illness Anxiety Disorder, MDD – Major Depressive Disorder, PDD – Persistent Depressive Disorder.

3.1.2.2 Correlational Studies

DA is associated with OCD severity and psychopathology in OCD patients

A number of studies investigated the relationship between DA, OCD severity, and psychopathology. Menzies et al. (2020; study 1) – using 79 patients with OCD and measuring DA with the MFODS – found that higher DA correlated positively with OCD severity. Verin et al. (2022) also observed similar findings whilst also using the MFODS to measure DA levels. Chawla et al. (2022) examined the role of existential concerns, including DA, in 48 OCD patients. Measuring DA using the ECQ, they also found significant correlations between higher OCD severity and higher DA levels. With a sample of OCD patients presenting to a psychology practice, Menzies and Dar-Nimrod (2017; study 1) explored the relationship between the DA, OCD severity and general psychopathology. Using the CLFD subscales as the measure of DA, they found moderate to large positive correlations between all subscales of CLFD scale and OCD severity, either by self-report (VOCI) or clinician ratings (ADIS-5L). Similar to Verin et al. (2022) DA scores were also positively related to worsened psychopathology as measured by distress, number of hospitalisations and medications, and total diagnoses. In study 2, Menzies et al. (2020) found that DA – measured by the ‘Death of Self’ and ‘Death of Others’ subscale from the CLFD measure – was also positively correlated with OCD severity. Chawla et al. (2022) also observed that beyond the association with DA, OCD severity was positively correlated with the other existential concerns namely, identity, guilt, isolation and meaninglessness. OCD severity was also associated with total ECQ score.

DA is associated with OCD subtypes

Menzies et al. (2020; study 1) also aimed to look at whether DA has a relationship with each subtype of OCD as captured by the VOCI. They found that DA, captured with the MFODS, had a positive relationship with subtype severity in people with OCD, with the subtypes under investigation being checking, contamination, hoarding, obsessions, ‘just right’ and indecisiveness. The relationship remained after controlling for confounds such as neuroticism, anxiety, and depression except for obsessions. Menzies et al. (2020; study 2) also found that CLFD subscales (‘Death of Self’ and ‘Death of Others’) had small to moderate positive relationships with subtype severity except for contamination. Additionally, they were also interested in whether the relationship between OCD severity and DA will differ depending on OCD subtype. Having categorised 211 participants into different subtypes based on their largest subtype Z score, they found that DA had a positive correlation with OCD severity in each subtype. They then compared the relationship between DA and OCD severity for each subtype and found that the strength of the relationship between DA and OCD severity was largely consistent across subtypes. The one exception was that this relationship was stronger for the ‘obsessions’ subtype

compared to the 'contamination' subtype. Chawla et al. (2022) also examined subtypes of OCD but focused on obsessions. They observed that DA was positively associated with *aggressive* obsessions but not sexual obsessions. However, there was a positive relationship between sexual obsessions and other existential concerns, namely guilt, isolation, identity, and meaninglessness.

Transdiagnostic role of DA

Two of the studies in this review assessed the effect of DA on psychopathology across a range of disorders including OCD. In a sample of 200 patients diagnosed with a range of anxiety disorders, Menzies and colleagues (2019) found a significant positive association between DA and overall psychopathology – evaluated using a composite score of variables such as number of lifetime diagnoses, hospitalisations and current medications – as well the severity of their condition. The authors concluded that was suggestive of DA being a transdiagnostic construct underlying anxiety disorders.

Menzies et al. (2021) explored the role of DA in a treatment-seeking OCD patients' pathway to developing OCD. The study measured DA using the MFODS and used the ADIS-5L to capture OCD. They found that those with higher levels of DA were more likely to develop OCD *after* developing other anxiety disorders. Moreover, DA was a significant predictor of whether OCD would be the first disorder as well as the number of disorders the patient developed. Those with higher DA had significantly more disorders before being diagnosed with OCD, averaging 2 disorders before OCD, compared with those with lower levels of DA, who averaged 0.24.

3.1.3 Quality assessment

The QuADS was chosen as a tool to assess study quality in this review because its items are applicable to both experimental and correlational studies. The initial inter-rater reliability, as measured by the intraclass correlation coefficient (ICC), was .638, which is classified as 'good' (Cicchetti, 1994). Overall, the quality of studies was variable, with a median QuADS score of 75% (range 47 – 91%). Correlational studies tended to be rated more highly than experimental studies. There was overlap in the performance on the items, such that studies of both designs tended to score poorly (≤ 2), for instance, on how well they provided information on recruitment data and inclusion of appropriate stakeholders. They also tended to score well (> 2) on items such as having sound theoretical underpinning and using appropriate study design and method of analysis.

4. Discussion

4.1 Summary of main findings

The papers included in this review consistently found that DA was positively associated with OCD. In clinical samples of participants with an OCD diagnosis, DA was positively associated with psychopathology, and this relationship was also observed in other anxiety conditions. Moreover, DA was positively associated with overall OCD severity, irrespective of the subtype of OCD, and DA was also positively associated with subtype severity. In relation to obsessions, DA was found to be positively associated with aggressive obsessions but not sexual obsessions. Beyond DA, OCD severity was also positively associated with other existential concerns, such as meaninglessness, isolation, and guilt. Those with higher levels of DA were also observed to be more likely to have developed more anxiety disorders prior to an OCD diagnosis. While this review includes papers that specifically address the relationship between DA and OCD, some of these papers also presented findings on related constructs. In mostly non-clinical samples, increasing MS was found to increase tendencies towards OCD behaviour, although these studies were limited to handwashing and mistake-checking related to scrupulosity. Overall, the studies with clinical samples provide evidence of a relationship between OCD and DA – perhaps one where DA plays a transdiagnostic role – and these findings are supplemented by experimental findings suggesting a causal role between MS and OCD symptoms.

The qualities of the studies based on the QuADS assessment tool was variable, with correlational studies scoring better than experimental studies. Overall, there was overlap in the performance on items for both types of studies. For example, both types tended to score poorly on items such as that related to adequate reporting of recruitment data and tended to score well on items such as that related to having a theoretical underpinning to the research.

4.2 Strengths, Limitations and Future Directions

A strength of the evidence presented in this review is that the correlational relationship between DA and OCD is supplemented by findings from experimental designs which points towards a convergence across methodologies. Nonetheless, the variability in the qualities between correlational and experimental studies, the use of non-clinical samples, and the lack of effect sizes reported in experimental studies present a limitation. Hence, future studies could investigate how MS affects OCD behaviours in clinical samples, especially in other subtypes of OCD. The evidence that DA underlies OCD could be further strengthened through controlled studies examining whether interventions that target reduction in DA also alleviates OCD symptoms.

Another strength was the consistency in findings between DA, OCD severity and psychopathology across different measures of DA. However, there are concerns about the psychometric properties of the available measures of DA, and the studies in this review did not use the best-established DA measures (Zuccala et al., 2019). The overall literature base for DA could benefit from the development of psychometrically sound DA measures or, in the short-term, from consistently using the best-available measures, especially those that are sensitive to clinical change. According to Zuccala et al. (2019), the Revised Collett-Lester Fear of Death Scale (Lester, 2004) scores best for sensitivity to clinical change, but it was found to be lacking in other psychometric properties. More recently, the Death Anxiety Beliefs and Behaviours Scale (Menzies et al., 2022) has been developed to address these limitations, with a particular focus on clinical utility.

The reviewed studies were mostly made up of correlational studies and they were especially strong in external validity and generalisability. However, the procedures in the methods section of the aforementioned studies were described inadequately, which may limit the extent to which they could be replicated. Moreover, most of the data is concentrated in Oceania, and generally from the same research team. Confidence in the evidence could be bolstered by investigations from a range of sources (Boccaccini et al., 2017).

Attitudes about death has been established as a complex interplay between factors such as culture, society, development, and religious beliefs. For example, extant literature has discussed how the salience of death may be influenced by one's stage of life (Menzies & Veale, 2022; Yalom, 2008) and that religious beliefs may help people cope with the fear of death (Pandya & Kathuria, 2021). Those with religious beliefs can still develop OCD (Nicolini et al., 2017), and it remains to be seen what role DA may play in such cases. Moreover, given that the studies in this review focused mainly on adults, future studies could look at the role of DA in older adults and youths with OCD. Future enquiries should also address the potential factors, such as traumatic experiences, self-esteem, need for control, and experiential avoidance, that may link DA with OCD.

Whilst the findings in this review suggest that DA may be a relevant mechanism underlying OCD, there was also evidence that DA may not relate with all symptoms related to OCD, as observed in its relationship to aggressive obsession but not sexual obsessions (Chawla et al., 2022). Moreover, given that Chawla et al. (2022) found that other existential concerns were also associated with OCD severity, future research could further incorporate other existential concerns in the investigations between DA and OCD, rather than focusing on DA alone.

4.3 Clinical Implications

The evidence reviewed thus far does not provide a strong case to suggest that DA causes OCD and it is premature to conclude that DA is universal to all cases of OCD. However, the evidence does provide a case for DA being associated with OCD and psychopathology in OCD patients. Hence, it may be worth considering how DA may be relevant to individual cases in clinical practice. The most widely cited therapeutic approach to OCD, namely Cognitive Behavioural Therapy (CBT) for OCD, has not traditionally given place to DA in models of case conceptualisation or intervention – although there are attempts to change this (McKay et al., 2015; Menzies & Veale, 2022; Öst et al., 2022; Salkovskis et al., 1998). In cases where DA may be contributing to the development or maintenance of OCD, it is encouraging that there is evidence that CBT can be effective in reducing DA (Menzies et al., 2018). It appears that existential themes may also be relevant in OCD, and these could also be explored in individual therapy, although this is subject to more investigations exploring the relevance of existential concerns in OCD.

Given that the research points to a transdiagnostic role of DA, it could have implications for future clinical research and practice. Clinical research has focused on traditional CBT without DA, and whilst they have repeatedly demonstrated that CBT can be effective for OCD in general, there are also indications that it does not lead to remission in all cases either post-treatment or follow up (Öst et al., 2022; Öst et al., 2015). Perhaps in cases where there is co-morbidity and complexity in OCD, research could focus on developing models that include and target DA and explore outcomes for such cases of complexity and co-morbidity.

4.4 Limitations

The current review has some limitations. Firstly, publication bias cannot be ruled given that the review included only peer-reviewed, published papers. Constraints in the databases searched and seeking research written in English could also contribute to limiting the breadth of research found. Similarly, the focus on empirical, primary investigations meant that other literature, such as case studies which may have contributed to the understanding of the role of DA in OCD were out of scope.

The QuADS (Harrison et al., 2021), whilst validated and an appropriate choice for this review, presents a limitation, in that some items focused on the *reporting* of the research, rather than solely on the methodological quality. Hence, the overall ratings of the studies may be impacted by scores on items that may be related to space limitations in journals. Additionally, the inter-rater reliability of the QuADS in this study was not ‘excellent’ although a consensus was reached through discussion. The reliability rating

may have improved following a trial of the QuADS on a few papers before independent ratings by the raters.

5. Conclusions

This review has provided consistent, provisional evidence supporting the claim that DA is associated with OCD symptomatology and that it may be transdiagnostic factor in other presentations. Findings were consistent across both experimental and correlational studies, although constrained by methodological limitations. There are yet many developments needed to establish confidence in the relationship between DA and OCD and to understand how DA should be addressed in evidence-based interventions for OCD. Given the consistent finding of an association between OCD and DA, though, clinicians should be cognisant to the possibility that DA may be relevant to clients with OCD. In all cases, thoughts and feelings about death may be explored as part of a formulation and where relevant, clinicians could ensure that it is addressed in their interventions.

References

- Abramowitz, J. S., D. Huppert, J., Cohen, A. B., Tolin, D. F., & Cahill, S. P. (2002). Religious obsessions and compulsions in a non-clinical sample: the Penn Inventory of Scrupulosity (PIOS). *Behaviour Research and Therapy*, *40*(7), 825-838. [https://doi.org/https://doi.org/10.1016/S0005-7967\(01\)00070-5](https://doi.org/https://doi.org/10.1016/S0005-7967(01)00070-5)
- Abramowitz, J. S., Deacon, B. J., Olatunji, B. O., Wheaton, M. G., Berman, N. C., Losardo, D., . . . Adams, T. (2010). Assessment of obsessive-compulsive symptom dimensions: development and evaluation of the Dimensional Obsessive-Compulsive Scale. *Psychological assessment*, *22*(1), 180-198.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19-32. <https://doi.org/10.1080/1364557032000119616>
- Arndt, J., & Goldenberg, J. L. (2017). Where Health and Death Intersect: Insights from a Terror Management Health Model. *Curr Dir Psychol Sci*, *26*(2), 126-131. <https://doi.org/10.1177/0963721416689563>
- Arndt, J., Routledge, C., Cox, C. R., & Goldenberg, J. L. (2005). The worm at the core: A terror management perspective on the roots of psychological dysfunction. *Applied and Preventive Psychology*, *11*(3), 191-213.
- Becker, E. (1973). *The denial of death*. Free Press.
- Boccaccini, M. T., Marcus, D., & Murrie, D. C. (2017). Allegiance Effects in Clinical Psychology Research and Practice. In *Psychological Science Under Scrutiny* (pp. 323-339). <https://doi.org/https://doi.org/10.1002/9781119095910.ch16>
- Breitbart, W. (2017). Existential guilt and the fear of death. *Palliative & supportive care*, *15*(5), 509-512. <https://doi.org/10.1017/S1478951517000797>
- Brown, T. A., & Barlow, D. H. (2014). *Anxiety and related disorders interview schedule for DSM-5 (ADIS-5)-adult and lifetime version: Clinician manual*. Oxford University Press.
- Burke, B. L., Martens, A., & Faucher, E. H. (2010). Two decades of terror management theory: a meta-analysis of mortality salience research. *Pers Soc Psychol Rev*, *14*(2), 155-195. <https://doi.org/10.1177/1088868309352321>
- Burns, G. L., Keortge, S. G., Formea, G. M., & Sternberger, L. G. (1996). Revision of the Padua Inventory of obsessive compulsive disorder symptoms: distinctions between worry, obsessions, and compulsions. *Behav Res Ther*, *34*(2), 163-173. [https://doi.org/10.1016/0005-7967\(95\)00035-6](https://doi.org/10.1016/0005-7967(95)00035-6)
- Castano, E., Yzerbyt, V., Paladino, M.-P., & Sacchi, S. (2002). I belong, therefore, I exist: Ingroup identification, ingroup entitativity, and ingroup bias. *Personality and Social Psychology Bulletin*, *28*(2), 135-143.

- Chawla, S., Menzies, R. E., & Menzies, R. G. (2022). Existential concerns in OCD with aggressive and sexual obsessions. *Journal of obsessive-compulsive and related disorders*, 32, 100710. <https://doi.org/https://doi.org/10.1016/j.jocrd.2022.100710>
- Chen, L., Benjamin, R., Lai, A., & Heine, S. (2022). *Managing the terror of publication bias: A comprehensive p-curve analysis of the Terror Management Theory literature*. <https://doi.org/10.31234/osf.io/kuhy6>
- Cicchetti, D. V. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological assessment*, 6(4), 284-290.
- Collett, L. J., & Lester, D. (1969). The fear of death and the fear of dying. *J Psychol*, 72(2), 179-181. <https://doi.org/10.1080/00223980.1969.10543496>
- Crusalis, B. S. (2014). Death Anxiety. In D. A. Leeming (Ed.), *Encyclopedia of Psychology and Religion* (pp. 464-465). Springer US. https://doi.org/10.1007/978-1-4614-6086-2_155
- Dar-Nimrod, I. (2022). Death Awareness and Terror Management Theory. In R. G. Menzies, R. E. Menzies, & G. A. Dingle (Eds.), *Existential Concerns and Cognitive-Behavioral Procedures: An Integrative Approach to Mental Health* (pp. 35-55). Springer International Publishing. https://doi.org/10.1007/978-3-031-06932-1_3
- Destrée, L., Brierley, M.-E. E., Albertella, L., Jobson, L., & Fontenelle, L. F. (2021). The effect of childhood trauma on the severity of obsessive-compulsive symptoms: A systematic review. *Journal of Psychiatric Research*, 142, 345-360. <https://doi.org/https://doi.org/10.1016/j.jpsychires.2021.08.017>
- Dykshoorn, K. L. (2014). Trauma-related obsessive-compulsive disorder: a review. *Health Psychol Behav Med*, 2(1), 517-528. <https://doi.org/10.1080/21642850.2014.905207>
- Enjedani, M., & Khodapanahi, M. K. (2011). Evidence that mortality salience exacerbate compulsive behaviour. *Procedia-Social and Behavioral Sciences*, 30, 899-901.
- Fergus, T. A., & Valentiner, D. P. (2012). Terror management theory and scrupulosity: An experimental investigation. *Journal of obsessive-compulsive and related disorders*, 1(2), 104-111.
- Greenberg, D., & Huppert, J. D. (2010). Scrupulosity: A unique subtype of obsessive-compulsive disorder. *Current Psychiatry Reports*, 12, 282-289.
- Greenberg, J., Kosloff, S., Solomon, S., Cohen, F., & Landau, M. (2010). Toward understanding the fame game: The effect of mortality salience on the appeal of fame. *Self and Identity*, 9(1), 1-18.
- Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The Causes and Consequences of a Need for Self-Esteem: A Terror Management Theory. In R. F. Baumeister (Ed.),

- Public Self and Private Self* (pp. 189-212). Springer New York.
https://doi.org/10.1007/978-1-4613-9564-5_10
- Greenberg, J., Pyszczynski, T., Solomon, S., Pinel, E., Simon, L., & Jordan, K. (1993). Effects of self-esteem on vulnerability-denying defensive distortions: Further evidence of an anxiety-buffering function of self-esteem. *Journal of Experimental Social Psychology, 29*(3), 229-251.
- Harrison, R., Jones, B., Gardner, P., & Lawton, R. (2021). Quality assessment with diverse studies (QuADS): an appraisal tool for methodological and reporting quality in systematic reviews of mixed- or multi-method studies. *BMC Health Serv Res, 21*(1), 144. <https://doi.org/10.1186/s12913-021-06122-y>
- Hayes, J., Schimel, J., Arndt, J., & Faucher, E. H. (2010). A theoretical and empirical review of the death-thought accessibility concept in terror management research. *Psychological bulletin, 136*(5), 699-739.
- Hayes, J., Schimel, J., Faucher, E. H., & Williams, T. J. (2008). Evidence for the DTA hypothesis II: Threatening self-esteem increases death-thought accessibility. *Journal of Experimental Social Psychology, 44*(3), 600-613.
<https://doi.org/https://doi.org/10.1016/j.jesp.2008.01.004>
- Hodgson, R. J., & Rachman, S. (1977). Obsessional-compulsive complaints. *Behaviour Research and Therapy, 15*(5), 389-395.
[https://doi.org/https://doi.org/10.1016/0005-7967\(77\)90042-0](https://doi.org/https://doi.org/10.1016/0005-7967(77)90042-0)
- Hoelter, J. W. (1979). Multidimensional treatment of fear of death. *Journal of consulting and clinical psychology, 47*(5), 996-999. <https://doi.org/10.1037//0022-006x.47.5.996>
- Iverach, L., Menzies, R. G., & Menzies, R. E. (2014). Death anxiety and its role in psychopathology: Reviewing the status of a transdiagnostic construct. *Clinical Psychology Review, 34*(7), 580-593.
<https://doi.org/https://doi.org/10.1016/j.cpr.2014.09.002>
- Klein, R. A., Cook, C. L., Ebersole, C. R., Vitiello, C., Nosek, B. A., Hilgard, J., . . . Christopherson, C. D. (2022). Many Labs 4: Failure to replicate mortality salience effect with and without original author involvement. *Collabra: Psychology, 8*(1), 35271.
- Lehto, R. H., & Stein, K. F. (2009). Death anxiety: an analysis of an evolving concept. *Res Theory Nurs Pract, 23*(1), 23-41. <https://doi.org/10.1891/1541-6577.23.1.23>
- Lester, D. (2004). The factorial structure of the revised Collett–Lester fear of death scale. *Death Studies, 28*(8), 795-798.
- Maxfield, M., John, S., & Pyszczynski, T. (2014). A terror management perspective on the role of death-related anxiety in psychological dysfunction. *The Humanistic Psychologist, 42*(1), 35-53.

- McKay, D., Abramowitz, J. S., Calamari, J. E., Kyrios, M., Radomsky, A., Sookman, D., . . . Wilhelm, S. (2004). A critical evaluation of obsessive–compulsive disorder subtypes: Symptoms versus mechanisms. *Clinical Psychology Review, 24*(3), 283-313. <https://doi.org/https://doi.org/10.1016/j.cpr.2004.04.003>
- McKay, D., Sookman, D., Neziroglu, F., Wilhelm, S., Stein, D. J., Kyrios, M., . . . Veale, D. (2015). Efficacy of cognitive-behavioral therapy for obsessive–compulsive disorder. *Psychiatry Research, 225*(3), 236-246. <https://doi.org/https://doi.org/10.1016/j.psychres.2014.11.058>
- Menzies, R. E., & Dar-Nimrod, I. (2017). Death anxiety and its relationship with obsessive-compulsive disorder. *Journal of Abnormal Psychology, 126*(4), 367-377.
- Menzies, R. E., & Menzies, R. G. (2023). Death anxiety and mental health: Requiem for a dreamer. *Journal of Behavior Therapy and Experimental Psychiatry, 78*, 101807. <https://doi.org/https://doi.org/10.1016/j.jbtep.2022.101807>
- Menzies, R. E., Sharpe, L., & Dar-Nimrod, I. (2022). The development and validation of the Death Anxiety Beliefs and Behaviours Scale. *British Journal of Clinical Psychology, 61*(4), 1169-1187. <https://doi.org/https://doi.org/10.1111/bjc.12387>
- Menzies, R. E., Sharpe, L., & Dar-Nimrod, I. (2019). The relationship between death anxiety and severity of mental illnesses. *British Journal of Clinical Psychology, 58*(4), 452-467. <https://doi.org/10.1111/bjc.12229>
- Menzies, R. E., & Veale, D. (2022). *Free yourself from death anxiety : a CBT self-help guide for a fear of death and dying*. London : Jessica Kingsley Publishers.
- Menzies, R. E., Zuccala, M., Sharpe, L., & Dar-Nimrod, I. (2018). The effects of psychosocial interventions on death anxiety: A meta-analysis and systematic review of randomised controlled trials. *Journal of anxiety disorders, 59*, 64-73. <https://doi.org/https://doi.org/10.1016/j.janxdis.2018.09.004>
- Menzies, R. E., Zuccala, M., Sharpe, L., & Dar-Nimrod, I. (2020). Subtypes of obsessive-compulsive disorder and their relationship to death anxiety. *Journal of obsessive-compulsive and related disorders, 27*, 100572.
- Menzies, R. E., Zuccala, M., Sharpe, L., & Dar-Nimrod, I. (2021). Are anxiety disorders a pathway to obsessive-compulsive disorder? Different trajectories of ocd and the role of death anxiety. *Nordic Journal of Psychiatry. 75*(2). 170-175 <https://doi.org/10.1080/08039488.2020.1817554>
- Menzies, R. G., Menzies, R. E., & Iverach, L. (2015). The role of death fears in obsessive–compulsive disorder. *Australian Clinical Psychologist, 1*(1), 6-11.
- Nicolini, H., Salin-Pascual, R., Cabrera, B., & Lanzagorta, N. (2017). Influence of culture in obsessive-compulsive disorder and its treatment. *Current Psychiatry Reviews, 13*(4), 285-292.
- Öst, L.-G., Enebrink, P., Finnes, A., Ghaderi, A., Havnen, A., Kvale, G., . . . Wergeland, G. J. (2022). Cognitive behavior therapy for obsessive-compulsive disorder in routine

- clinical care: A systematic review and meta-analysis. *Behaviour Research and Therapy*, 159, 104170. <https://doi.org/https://doi.org/10.1016/j.brat.2022.104170>
- Öst, L.-G., Havnen, A., Hansen, B., & Kvale, G. (2015). Cognitive behavioral treatments of obsessive–compulsive disorder. A systematic review and meta-analysis of studies published 1993–2014. *Clinical Psychology Review*, 40, 156-169. <https://doi.org/https://doi.org/10.1016/j.cpr.2015.06.003>
- Pandya, A.-k., & Kathuria, T. (2021). Death Anxiety, Religiosity and Culture: Implications for Therapeutic Process and Future Research. *Religions*, 12(1), 61. <https://www.mdpi.com/2077-1444/12/1/61>
- Pyszczynski, T., Greenberg, J., & Solomon, S. (1999). A dual-process model of defense against conscious and unconscious death-related thoughts: An extension of terror management theory. *Psychological Review*, 106(4), 835-845. <https://doi.org/10.1037/0033-295X.106.4.835>
- Pyszczynski, T., Lockett, M., Greenberg, J., & Solomon, S. (2020). Terror Management Theory and the COVID-19 Pandemic. *Journal of Humanistic Psychology*, 61(2), 173-189. <https://doi.org/10.1177/0022167820959488>
- Pyszczynski, T., Solomon, S., & Greenberg, J. (2015). Chapter One - Thirty Years of Terror Management Theory: From Genesis to Revelation. In J. M. Olson & M. P. Zanna (Eds.), *Advances in Experimental Social Psychology* (Vol. 52, pp. 1-70). Academic Press. <https://doi.org/https://doi.org/10.1016/bs.aesp.2015.03.001>
- Rosenblatt, A., Greenberg, J., Solomon, S., Pyszczynski, T., & Lyon, D. (1989). Evidence for terror management theory: I. The effects of mortality salience on reactions to those who violate or uphold cultural values. *J Pers Soc Psychol*, 57(4), 681-690. <https://doi.org/10.1037//0022-3514.57.4.681>
- Sætrevik, B., & Sjøstad, H. (2022). Mortality salience effects fail to replicate in traditional and novel measures. *Meta-Psychology*, 6. <https://doi.org/10.15626/MP.2020.2628>
- Salkovskis, P. M., Forrester, E., & Richards, C. (1998). Cognitive–behavioural approach to understanding obsessional thinking. *British Journal of Psychiatry*, 173(35), 53-63. <https://doi.org/10.1192/S0007125000297900>
- Schindler, S., Reinhardt, N., & Reinhard, M.-A. (2021). Defending one's worldview under mortality salience: Testing the validity of an established idea. *Journal of Experimental Social Psychology*, 93, 104087. <https://doi.org/https://doi.org/10.1016/j.jesp.2020.104087>
- Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of evaluation in clinical practice*, 18(4), 746-752.
- Solomon, S., Greenberg, J., & Pyszczynski, T. (2015). *The Worm at the Core: On the Role of Death in Life*. New York: Random House

- Sookman, D., Abramowitz, J. S., Calamari, J. E., Wilhelm, S., & McKay, D. (2005). Subtypes of obsessive-compulsive disorder: Implications for specialized cognitive behavior therapy. *Behavior Therapy*, *36*(4), 393-400.
[https://doi.org/https://doi.org/10.1016/S0005-7894\(05\)80121-2](https://doi.org/https://doi.org/10.1016/S0005-7894(05)80121-2)
- Strachan, E., Schimel, J., Arndt, J., Williams, T., Solomon, S., Pyszczynski, T., & Greenberg, J. (2007). Terror mismanagement: Evidence that mortality salience exacerbates phobic and compulsive behaviors. *Personality and Social Psychology Bulletin*, *33*(8), 1137-1151. <https://doi.org/10.1177/0146167207303018>
- Thordarson, D. S., Radomsky, A. S., Rachman, S., Shafran, R., Sawchuk, C. N., & Hakstian, A. R. (2004). The Vancouver obsessional compulsive inventory (VOCI). *Behaviour Research and Therapy*, *42*(11), 1289-1314.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., . . . Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, *169*(7), 467-473.
<https://doi.org/10.7326/M18-0850>
- van Bruggen, V., ten Klooster, P., Westerhof, G., Vos, J., de Kleine, E., Bohlmeijer, E., & Glas, G. (2017). The Existential Concerns Questionnaire (ECQ)—Development and Initial Validation of a New Existential Anxiety Scale in a Nonclinical and Clinical Sample. *Journal of Clinical Psychology*, *73*(12), 1692-1703.
<https://doi.org/https://doi.org/10.1002/jclp.22474>
- Verin, R. E., Menzies, R. E., & Menzies, R. G. (2022). OCD, death anxiety, and attachment: what's love got to do with it? *Behav Cogn Psychother*, *50*(2), 131-141.
<https://doi.org/10.1017/s135246582100045x>
- Watson, D., & Wu, K. D. (2005). Development and validation of the Schedule of Compulsions, Obsessions, and Pathological Impulses (SCOPI). *Assessment*, *12*(1), 50-65. <https://doi.org/10.1177/1073191104271483>
- Wisman, A., & Goldenberg, J. L. (2005). From the grave to the cradle: evidence that mortality salience engenders a desire for offspring. *Journal of personality and social psychology*, *89*(1), 46-61. doi: 10.1037/0022-3514.89.1.46.
- Yalom, I. D. (1989). *Love's executioner: And other tales of psychotherapy*. Basic Books.
- Yalom, I. D. (2008). *Staring at the sun : overcoming the terror of death*. San Francisco : Jossey-Bass.
- Zuccala, M., & Menzies, R. E. (2022). Fears of Death and Their Relationship to Mental Health. In R. G. Menzies, R. E. Menzies, & G. A. Dingle (Eds.), *Existential Concerns and Cognitive-Behavioral Procedures: An Integrative Approach to Mental Health* (pp. 57-73). Springer International Publishing.
https://doi.org/10.1007/978-3-031-06932-1_4

Zuccala, M., Menzies, R. E., Hunt, C. J., & Abbott, M. J. (2019). A systematic review of the psychometric properties of death anxiety self-report measures. *Death Studies*, 46(2), 1-23. <https://doi.org/10.1080/07481187.2019.1699203>

An evaluation of group STrategies for Relatives (START) for carers of people with dementia

Benjamin Kwapong

Trainee Clinical Psychology (University of Bath)

bk513@bath.ac.uk

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Internal supervisor: Dr Ashley Vanstone

External/field supervisor: Dr Anna Strudwick

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Rationale: This is a quality journal that welcomes articles with qualitative methods relevant to health care. The journal also has contributions from a range of disciplines, covers a range of topics, including the experiences of caregivers, and has a multi-disciplinary readership.

Introduction

Dementia, which is an umbrella term for brain diseases such as Alzheimer's disease, leads to deterioration in cognitive ability and, consequently, functional ability (Franchi, 2016; Robinson, 2016). There is currently no cure for dementia, meaning there is continual degeneration until death (Arvanitakis et al., 2019; Sachs, 2009). There are approximately 885 000 people living with dementia in the UK, and this is expected to rise in line with life expectancy increases in the UK and worldwide (Wittenberg et al., 2020; Wittenberg et al., 2019). Often, dementia may lead to hospitalisation or formal care provision, which can be costly for the individual, their families, or the state. Dementia, therefore, poses a growing problem for contemporary society (Wong & Knapp, 2020).

In some cases, those living with dementia continue to reside at home with increased support from informal caregivers (Brodaty, 2009). Informal caregivers are those who take a principal role in providing care for people living with dementia at home; they may be relatives, spouses, or friends, and they make up the majority of caregivers (McCabe et al., 2016). Their input reduces hospitalisation and helps bring about meaningful living for the person with dementia (Harding et al., 2015). Informal caregivers, therefore, have an important role in managing the consequences of dementia.

However, the input of informal caregiving has significant economic, social, and health costs. Providing care may lead to loss of employment and reduced social involvement, and there is a well-established link between behavioural and psychiatric symptoms of dementia and a range of adverse mental health problems (Brodaty, 2009; Xu et al., 2017). Dementia caregiving has been associated with increased anxiety, depression, and physical health issues such as problems with the cardiovascular system (O'Dwyer et al., 2016; Richardson et al., 2013). Additionally, dementia caregivers are more likely to develop mental health problems than non-carers and carers of other conditions, with 40% of dementia caregivers developing clinically significant depression and anxiety, which can lead to a reduction in the quality of caregiving (Livingston et al., 2014).

The challenge that dementia poses has been recognised globally and in the UK at the National Health Service (NHS) and governmental level (Department of Health, 2015; NHS Improvement, 2017). In the UK, initiatives have been developed to improve standards for dementia care, ranging from improving the process of diagnosis to providing efficacious and timely post-diagnostic support for the person living with dementia and their caregivers. In the absence of a cure, it has been suggested that resources should be redirected to efforts aimed at ensuring good quality care for people with dementia and their carers, especially given that this need is more imminent (Wong & Knapp, 2020).

The National Institute for Health and Care Excellence (NICE) recommends that caregivers should be provided with psychoeducation and skills training when possible as part of a group setting. This is with the aim of providing them with tools to cope with the challenges of caring for a loved one with dementia and to prevent deterioration in their own mental health (NICE, 2018). The wider body of literature, including a mixed studies review, supports this (Bressan et al., 2020; Zwaanswijk et al., 2013).

In clinical practise, post-diagnostic support for caregivers may include practical, emotional, and informational support to better care for the person living with dementia (Watts et al., 2013). Examples may be formal or informal peer support groups and groups aiming to educate and provide advice about coping with dementia, and these may be provided by the NHS. It may also involve groups aimed at reducing psychological problems such as anxiety and depression (Watts et al., 2013). Carers may also be able to access talking therapies via Improving Access to Psychological Therapies (IAPT) referrals for depression and anxiety. Despite the variety of post-diagnostic support available, the need for cost-effective, evidence-based psychological treatments for dementia caregivers suitable for the NHS context led to the development of the STrAtegies for RelaTives (START) programme. It was designed to be pragmatic and delivered by psychology graduates, such as assistant psychologists under supervision within the NHS (Livingston et al., 2014).

The original START programme is an eight-session manual-based therapy delivered individually to family caregivers of people living with dementia (Amador et al., 2021). The intervention is based on principles from Cognitive Behavioural Therapy (CBT) in combination with theoretical insight from Lazarus and Folkman's stress appraisal and coping response model (Lazarus & Folkman, 1984; Livingston et al., 2014). These principles underpin the aims of the intervention, which is to provide family caregivers with strategies to bolster their coping to match the demands of caregiving whilst learning CBT techniques. Together, these principles are aimed at alleviating depression and anxiety (Livingston et al., 2014). The START programme is well supported by evidence, with Randomised Controlled Trials (RCTs) demonstrating a reduction in depression and anxiety, with effectiveness shown even at a 6-year follow-up (Livingston et al., 2019). Furthermore, it has been demonstrated to be scalable and can be delivered by staff in the third sector (Amador et al., 2021). It has also been successfully used in a variety of cultural contexts (Kashimura et al., 2020) and delivered online (Loi et al., 2022). A qualitative study using a survey approach found that even after two years, participants were still using techniques from START (Sommerlad et al., 2014).

As mentioned earlier, NICE guidance recommends support for carers in the form of a group where possible. Whilst individually delivered interventions have their

advantages – such as easily tailoring information – there are indications that family carers may benefit from the social aspects of group interventions. This may include the opportunity to form connections with others, which is especially important as they often report isolation (Loi et al., 2022; Malhotra & Baker, 2022). Group therapy may have other advantages, such as learning from others and being aware that others share one's difficulties (Gidron, 2013). Another rationale for group therapy in this context is that it may be the most efficient way of meeting the potentially rising demand for mental health services needed for caregivers of those with dementia (Malhotra & Baker, 2022). However, advantages notwithstanding, it is unclear whether group interventions are more economical (Biggs et al., 2020; Chien et al., 2011; Hoddinott et al., 2010).

Given the NHS' role in delivering services to support caregivers of people living with dementia, group interventions may be particularly useful. Group START was developed in an NHS Community Mental Health Team (CMHT) located in the Southwest of England. This intervention closely followed the principles and structure of the original START programme and was co-developed by staff in the CMHT for Later Life and IAPT and delivered by two members of staff from those teams. Different topics were delivered to the group over eight weeks. This included challenging unhelpful thoughts, scheduling pleasant activities, managing challenging behaviours, improving communication, and planning for the future. Each session ended with a new relaxation technique that participants could practise in addition to a relevant session-specific homework task which was reviewed before each session. Time was allocated to didactically learning skills and tools and discussing caregiving experiences.

There is a drive for continual improvement and evaluation of services within the NHS to ensure greater quality (Craig, 2018). Indeed, there are calls for quality improvement to be embedded across all levels of the NHS, including leadership and clinical intervention (Drew & Pandit, 2020). Part of quality improvement involves applying specific techniques, such as the Plan, Do, Study, Act (PDSA) cycle (Laverentz & Kumm, 2017). It is within this context that the group START programme is being evaluated. Following the 'Do' stage of the cycle, the current evaluation aims to 'Study' the delivery of group START.

Aims

The current evaluation aims to look at the following:

- How did depression and anxiety scores of group START participants change during the course of the intervention?

- What were caregivers' experiences of doing group START? What were their thoughts on the acceptability of the intervention and their suggestions for improvement?

Method

Design

This evaluation utilised a mixed-methods design that included descriptive analysis of outcome measures and qualitative analysis of focus group data.

Setting, Procedure, and Ethics

Group START was designed to *specifically* meet the psychological and emotional needs of dementia caregivers in order to complement other service provisions, which included, for instance, dementia education service. The group ran for eight weeks between November 2019 and January 2020, with the focus group occurring after January 2020 before the global COVID-19 pandemic. Participants were invited to attend the focus group after completing group START. The focus group was coordinated and facilitated by an assistant psychologist in the service.

Participants provided verbal and written consent in accordance with the local NHS trust policy. It was approved as a service-related project by the University of Bath and the host NHS trust.

Participants

Identified participants of group START were caregivers who were under the care of the Later Life and IAPT team in the local NHS trust. Eight participants signed up, but six attended group START. Of the six, four people participated in the focus group. Participants were mostly white British, female, and retired. They attended an average of seven sessions, with a range of five to eight sessions. Where captured, participants were either diagnosed with stress only or stress with low mood, and anxiety (see Table 2.1).

Measures

The following measures were used to assess the severity of mental health and were collected weekly:

- *Patient Health Questionnaire-9* (PHQ-9; Kroenke et al., 2001). PHQ-9 is a validated, widely used measure in clinical practice to measure depressive symptoms in adults and has been shown to have good psychometric properties, e.g., reliability (Cronbach's $\alpha = 0.89$), and sensitivity in measuring depressive symptoms. The following clinical cut-off points are used to determine the severity of symptoms: a score of 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe), and 20 and above (severe).

- *The Generalised Anxiety Disorder Assessment (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006)* is a commonly used measure of anxiety in clinical practice. It is often used with adults and has been demonstrated to have good reliability (Cronbach $\alpha = 0.92$) and validity, such as construct validity. The following clinical cut-offs for severity are widely accepted: 5-9 (mild), 10-14 (moderate), and 15 and above (severe).

Data analysis

Quantitative Analysis. A descriptive analysis of the means and standard deviations of depression and anxiety scores was analysed using Microsoft Excel.

Qualitative Analysis. The data was initially transcribed and anonymised by an assistant psychologist working in the Later Life service. Analysis was done solely by the author (B.K.) and was guided by the *reflexive* Thematic Analysis (RTA) (Braun & Clarke, 2019, 2021a, 2021b). The acknowledgment and emphasis on the interpretative and active role of the researcher in RTA made it a suitable choice for this research, which aimed to embrace the qualitative approach to understand participants' experiences. This feature is not unique to RTA, but it was further chosen over other qualitative approaches because of its theoretical flexibility and, subsequently, its applicability to a range of research topics (Lyons & Coyle, 2021). The following theoretical positions and decisions were taken following the initial reading of the data:

- a (critical) realist epistemological stance, where participants' descriptions of their experience were assumed to be the true reflection of reality, though shaped by the researcher's interpretation;
- coding developed using a 'semantic' approach, i.e., describing and summarising the explicit meaning of data, and a 'latent' approach, i.e., where applicable, coding the data in a way that looks beyond the explicit description of participants and captures participants' underlying ideas and assumptions;
- themes were developed using an 'inductive' approach, i.e., from within the data, but also using a 'deductive' approach, i.e., developed to answer aspects of the research question.

The analytic process in RTA involves six phases, which are outlined in Table 2.3. Themes were typically developed as meaningful patterns across data sets, in accordance with RTA. NVivo 12, a qualitative research software from QSR International, was used to store, organise, and support the analysis of the data from the focus group.

Discussions with peers as part of an RTA working group were used as a means of maintaining fidelity to RTA. Braun and Clarke argued that trustworthiness and reliability in 'Big Q' qualitative analytic methods like reflexive thematic analysis are determined by

fidelity to a systemic approach to analysis, with increased transparency of the researcher's own characteristics, which may shape and contextualise the analytic process and product (Braun & Clarke, 2019; Lyons & Coyle, 2021). In line with this, B.K. kept a journal of emerging ideas and decision making throughout the analysis process and outlined key characteristics that may shape decisions throughout the process (see Table 2.2).

Table 2.1

Characteristics of participants

Characteristics	Carer N = 6 Mean (SD) or n (%)
Age	71.3 (5.85)
Gender	
Female	4 (66%)
Male	2 (33%)
Ethnicity	
White British	5 (83%)
White European	1 (16%)
Mean number of sessions attended	7 (1.1)
Diagnosis	
Stress	2 (33%)
Stress, anxiety and low mood	2 (33%)
Unknown	2 (33%)
Employment Status	
Retired	3 (50%)
Part-time employment	1 (16%)
Carer	1 (16%)
Unknown	1 (16%)

Table 2.2*Characteristics of researcher undertaking the evaluation*

Gender	Male
Occupation (at the time of the study)	Trainee Clinical Psychologist
Credentials	BSc Psychology, MRes Psychology
Experience and training	Qualitative experience in Grounded Theory, Interpretative Phenomenological Analysis, Thematic Analysis, and Conversation Analysis.
Relationship with participants and research team	Unknown to participants hence 'outsider' member. External to research team.
Motivations	To fulfil requirements of Doctorate in Clinical Psychology at the University of Bath. No vested interest or conflict of interest related to this project.

Results

Quantitative. Six participants provided scores for pre- and post-measures of anxiety and depression. Mean scores for GAD-7 were 9.1 (SD = \pm 6.8) pre-therapy and 9.5 (SD = \pm 5) post-therapy. For the PHQ-9, participants had a mean score of 10.5 (SD = \pm 7) pre-therapy and 8.5 (SD= \pm 6.2) post-therapy. This suggests an average shift from "moderate" to "mild" depression, whilst anxiety ratings remained "mild" pre- and post-therapy.

Table 2.3*Description of the phases of reflexive thematic analysis*

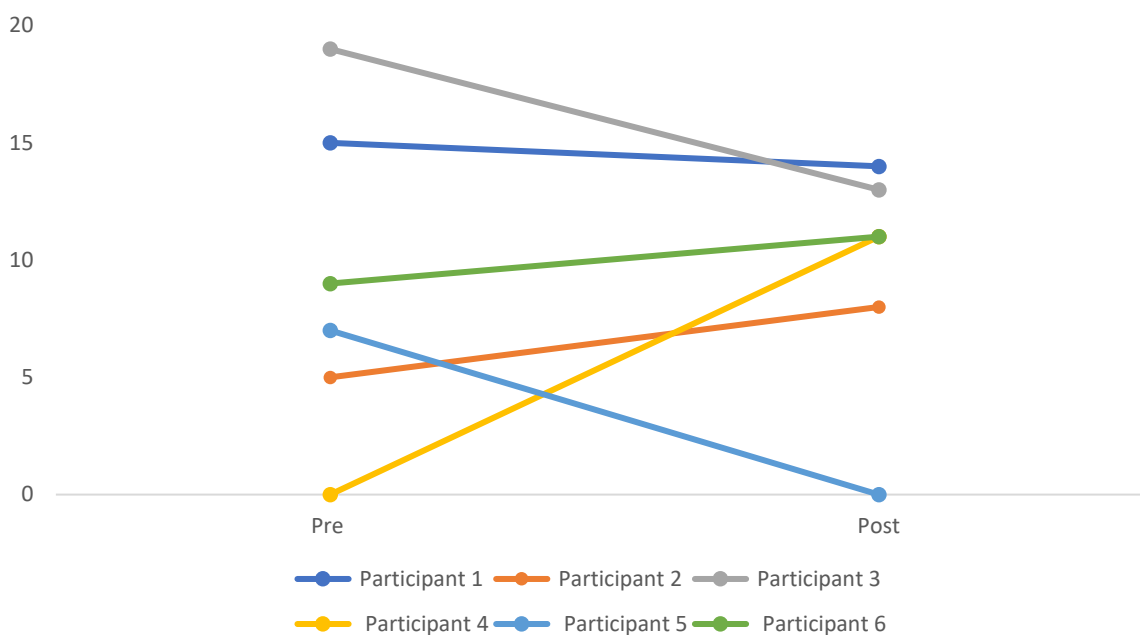
Phase of reflexive thematic analysis (Braun & Clarke, 2019, 2021)		How it was used in this study
Phase 1	Data familiarisation	Reading transcript several times, making notes of salient ideas, potential codes, and themes.
Phase 2	Data coding	Reading through data, coding data segments that may be relevant for research question, in line with theoretical positions outlined above.
Phase 3	Initial theme generation	Codes were grouped into potential themes based on the initial ideas developed. The themes here were meaningful patterns that helped answer the research question, summarised the data, and were the most meaningful aspects of the participant experience.
Phase 4	Developing and reviewing theme	Potential themes were checked and reconsidered using the following questions: Is this a theme or a code? Does it answer the research question? Are there enough meaningful data to support this?
Phase 5	Refining and naming themes	Themes were finalised, and the essence of each theme was identified and described. Each theme was subsequently named.
Phase 6	Reporting	Key themes and subthemes were developed and written, and a thematic map was developed and presented.

A closer look at GAD-7 scores highlighted that three participants had an increase in anxiety, whilst the rest experienced a decrease. All but two changes were not clinically

significant. For these two, there was an increase from non-clinical levels to “moderate” and a decrease from “mild” range to non-clinical range (see Figure 2.1).

Figure 2.1

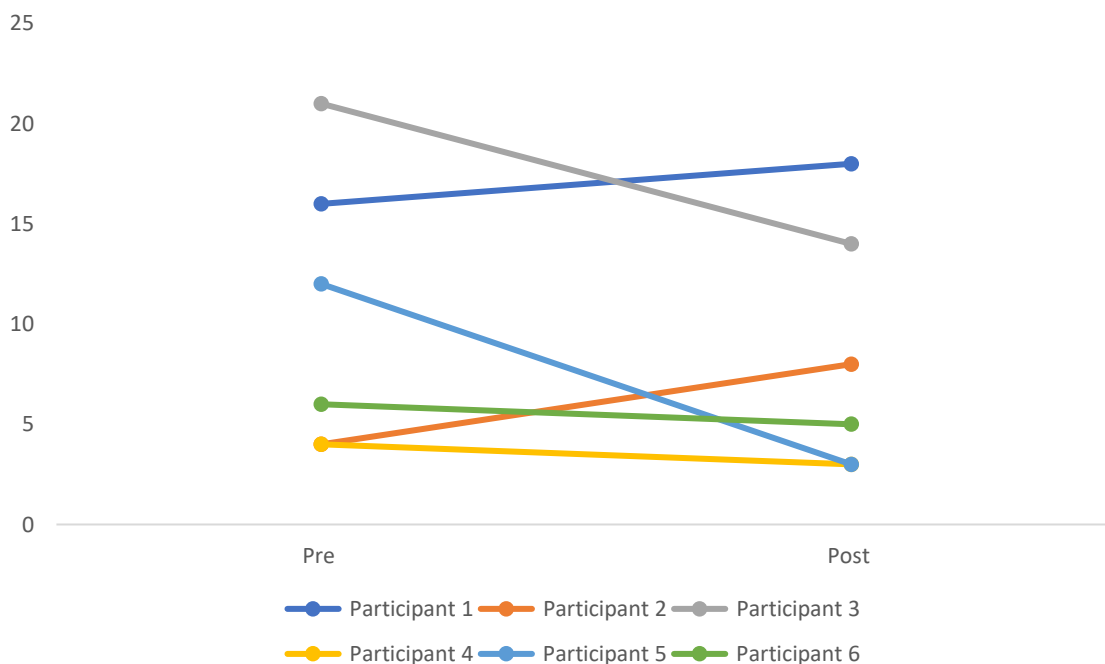
Pre- and post- GAD-7 scores for each participant



PHQ-9 scores revealed a decrease in ratings for all but two participants. For the two, there was an increase from a non-clinical score to “mild”, Whilst the other reported a clinically insignificant increase of two points within the “moderately severe” range (see Figure 2.2).

Figure 2.2

Pre- and post- PHQ-9 scores for each participant



Qualitative. Four participants attended the focus group. Three themes were identified, with two subthemes for the first two themes (see Figure 2.3 for the thematic map). The following analytic narrative reflects the theoretical position adopted for this research, namely the critical realist position. That is, the ‘real’ experiences of participants are presented as *understood* by the researcher.

1. Value of being in a group

This theme and its subthemes highlight how being in a group setting and being part of a group constituted a significant and valuable part of the experience for participants of the group START programme.

1.1 Opportunity to share

Group members voiced that they appreciated sharing a space with other people whom they felt understood their difficulties and experiences. Participants frequently discussed feeling isolated and alone with their challenges, and there was a sense that other people in their lives – for example, neighbours, family members who were not involved in the care for the person with dementia, and some professionals did not truly understand how dementia presented in their day-to-day experience and what it was like caring for someone with dementia. This often manifested in how others interacted with the person with dementia, and this lack of understanding in some cases decreased social contact in the process:

But the other thing I find, even with my husband’s friends... they talk to him and if he doesn’t come out with what they would expect him to come out with, they say ‘you do remember that – of course, you remember that’. And I look at them and think... You know he’s not well. But you’re pushing for that (P3)

Participants reported a different experience when in the midst of other attendees in the START programme. Though there were varying levels of experiences, overall, there was a general sense of a shared understanding of the lived experience and challenges of caring for someone with dementia, as described by one participant: “... we all understand one another. Because it’s actually living with it isn’t it?! ... I think for me it was, again as [P1] said, it was like-minded people. People that are experiencing real problems with their loved ones...” (P3).

Participants often used the group as an opportunity to share with other people who they felt understood them. This was really valued, as opportunities to share with others in

their lives were lacking: “And I think that’s a good thing that you can share it. As you said you dish the garbage because you can’t dish it to your relatives” (P4).

This process manifested in the focus group: participants spent much of the time sharing their difficulties and often shared how they could relate to each other’s experiences. This process appeared to be facilitated by a number of factors. Participants felt that the nature of the course structure, especially being given time to discuss their experiences, helped. Additionally, participants felt that the size of a group had an impact. They felt having a small group helped them build a strong relationship and hence, confidence to share. Practically, it allowed each person sufficient opportunity to share their experiences as described by P2: “... everyone could dish a comment into the mix” and P1: “I don’t know about anybody else but it was a close group, like a family really... We all got on well... it was a nice number”. P4 tells this in more detail:

You know, get rid of whatever you brought from home, and then kind of just reviewing what we did last time. And how did we get on with the exercises. And then we move onto the new things. So it was... I think it was a good balance... It was just a nice sharing.

1.2 Opportunity to learn (from others)

Through the process of sharing experiences, participants were able to learn from one another’s expertise in addition to learning from the course content, which they felt was comprehensive. This was also apparent in the focus group, where participants shared their experiences and others immediately tried to provide solutions or ideas. Overall, participants spoke about finding it useful to hear from others and vicariously learning from their experience to cope:

You know, I mean, everybody was bringing valuable stuff. Umm, you know, yours was quite umm, a sort of, I thought you’d got a really intelligent way of handling it. And I thought, oh gosh, you know... I just think I don’t have an intelligent way of handling it (P2).

This was especially true for one participant, who felt inexperienced and had been looking forward to learning from others and had incorporated things they had learned from others into their life as a caregiver:

“Well, ... I’d never experienced anything with dementia before... I was picking up on what other people were doing. The course brought us all together, and that’s the key

element of what you could pick out of the course. How other people handle situations” (P1).

Participants felt supported by others and they felt a follow-up group would be helpful: “And it’s things like that, where we’re feeding off one another and if we lost that, you go down – how the hell am I going to cope with this?” (P1). P4 also added: “Yea, it [follow on group] would be beneficial, I think. It just kind of keeps... I don’t know, it’s, it’s just a nice group and a nice support.”

2. (Salient) Impact of Group START

This theme captures participants’ expressions that attending the group had tangible impacts on their lives and brought about changes. Participants discussed how they had learned new things on the course that they would not have otherwise done and how the course had changed their attitude and coping skills. The impact of attending the course was seen in the two sub-themes below:

2.1 Aiding coping with difficulties

It was clear that participants had a lot of challenges caring for their family members though it appeared that attending the group provided them with ways of coping. In some cases, they used specific tools, for instance, grounding or emotional management learned from the group, to help them cope with challenging situations:

Yea I find it you analyse things more, isn’t it. You’ve got the skill now to think about it and analyse it – well what is happening. Okay this is happening, and then you look in your toolbox and think, I can do this. I can take a deep breath, or I count to 10 or I ground myself or I go out of the room (P4).

Interestingly, participants noted that there had been a shift in their attitude toward the difficulties they experienced. Participants spoke about experiences that suggested they were more patient and tolerant, and that they had developed greater awareness of the needs of the person they cared for and how they handled situations. They shared how automatic reactions were now replaced with thoughtful responses; that is, they were able to regulate their emotional response and then apply the knowledge gained from attending the group:

I thought that the trigger mechanism was a good example. With things happening, you’ve got to be able to think, ‘well what triggered that off?’. That was a good part of the

course. Something which I hadn't thought of. As in, they made you think, she reacting this way... what made her react that way? (P1).

2.2 Encouraging to look after self

Participants also spoke about how they had made a definite change to look after themselves following the course. This occurred through increased awareness of their emotional well-being following observation of themselves, which may have been facilitated by completing outcome measures as illustrated by P4: "... that information... that can also be useful, you know to reflect on those sorts of things – oh what happened there, okay how could I handle that differently..." and P3: "...I was really surprised at it but, then I could see exactly where I was really stressed out, by the graph. And I knew I had been at that particular time..."

Participants then discussed how, as a result of the course, they gave themselves permission to take care of themselves amidst caring for the person with dementia, which would not have otherwise happened: "The thing that kept coming up time and time again was that umm... you gotta put yourself first, you've got to look after yourself" (P1). "Yea cos I was saying no to people wanting to have a coffee with me because I thought, I need to be around, you know.... I don't know... I feel alright about it" (P2).

Yea. And I don't try to overdo things either. I was always running around, here, there, and everywhere. And now, I've had other issues in the family, but I've just found myself going at a bit of a slower pace (P3).

3. (Lack of) challenges and recommendations

Participants generally found attending the group positive and felt the set-up and structure were suitable and acceptable, with few barriers to attending the group. Interestingly, they identified minor issues with the group or its content. Participants spoke about how the group had met their expectations, although perhaps they felt this may change with greater reflection and time. Indeed, one participant felt that group START would be helpful for other carers of people with dementia and that it should be offered more widely: "You know, and I think, it is, it should be offered more widely" (P4).

Understandably, participants had challenges completing tasks in between sessions. Some felt there was pressure to complete it, whilst others felt this was not the case; however, all agreed that demands of care and other barriers, e.g., time constraints and stress, can push them to deprioritise out of session tasks: "As I've said, we've had other issues in the family, illness and... it just swamped me to be quite honest" (P4). "I

was ill, I was in pain all over the last, well since three weeks before Christmas... it just seemed to be one endless train of things to do, all the time" (P2).

Despite their positive perspectives, participants felt the group was missing an expert, specialist, or a source of information to whom they could contact in between sessions with questions, as they felt they often wanted this but could not attain it.

Discussion

This project, in accordance with the NHS' drive for improving services, aimed to evaluate group START, an intervention developed for reducing anxiety and depression in caregivers of those with dementia. Descriptive quantitative analysis revealed that, for pre- and post-intervention scores, on average, participants shifted from "moderate" to "mild" for depression, whilst scores for anxiety remained at "mild". Qualitative analysis – using reflexive thematic analysis – revealed three themes with four subthemes (see Figure 2.3). Participants' experiences were mainly related group processes and the components and impact to the group START programme. From the responses available, participants had few problems with the intervention, suggesting that participants found attending group START acceptable and feasible. Indeed, this evaluation provides preliminary encouragement that group START could be considered in routine NHS service delivery for caregivers of people with dementia.

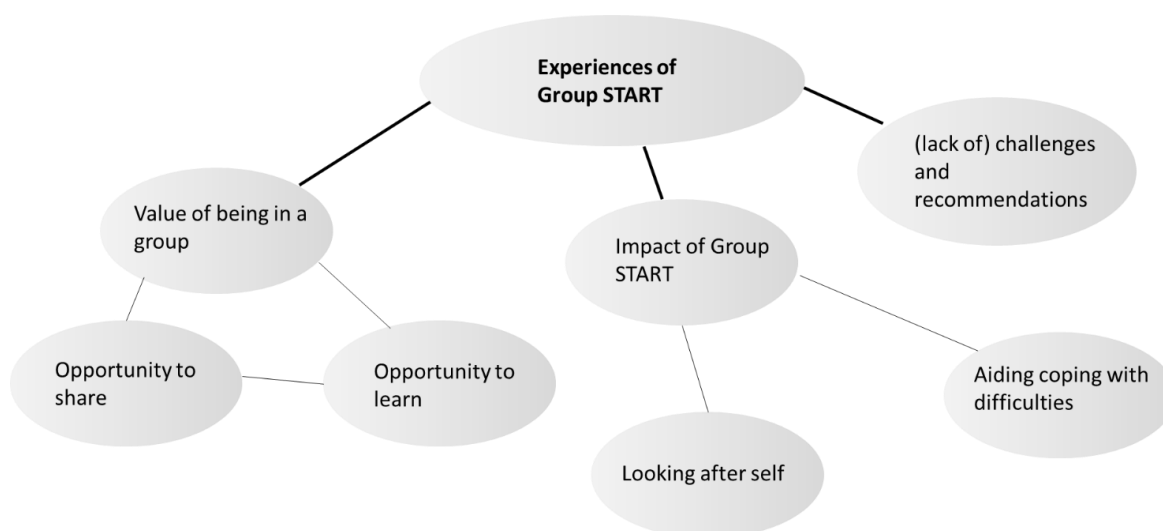
Perhaps unsurprisingly, the important aspects of group START for participants matched the outlined therapeutic benefits of group therapy, such as being able to share experiences, develop hope, learn from each other, and support and trust others (Malhotra & Baker, 2022). It may be, then, that group therapy allows participants to gain beyond the content and specific learning of techniques and tools. The social aspects of group therapy may even be more important to, and relevant for caregivers of those with dementia, given reports that they experience loneliness and isolation as a result of caregiving.

Some of the recommendations that participants raised also appeared to be pertinent in the wider literature for caregivers of those with dementia. In addition to being supported by tailored and flexible services, caregivers' needs were highlighted in the literature as needing a central expert point of contact; understanding how to access healthcare services; receiving appropriate and timely information; being provided with guidance around exploring alternative information; and finding a balance between caregiving and time for themselves, including being supported to take respite without feeling guilty (Bressan et al., 2020). Respite, or being able to have time away from caregiving responsibilities, has been a pertinent topic in dementia caregiving. As highlighted in this evaluation, emphasising its importance may be useful in promoting the well-being of caregivers. It may be beneficial to incorporate all the highlighted

needs of caregivers in group services within the NHS, including group START.

Figure 2.3

Thematic map



Note. Darker, thicker line denotes relationship between concept and themes and thinner lines representing relationship between themes and subthemes.

Given the information highlighted so far, it may therefore be appropriate to offer group START to caregivers. In doing so, services would meet the needs of dementia caregivers as well as adhere to NICE guidelines. However, it is important to still recognise that group interventions may not be suitable for everyone, and in some cases, individual START may still be necessary. The nature of group work means it may be more suitable for those who are extroverted and comfortable sharing difficult and personal experiences with other group members; participants highlighted this within the focus group (Malhotra & Baker, 2022). In practice, this may be difficult, as resource limitations mean group therapy may be all that is available.

For this evaluation, participants discussed how having a group of six enabled opportunities to share information. The small number also facilitated group processes such as building camaraderie. Participants felt this group size was ideal, and this has been echoed in the literature, where recommended group sizes have ranged between five to 10 members as dysfunctional processes begin to occur once these group sizes are exceeded (Biggs et al., 2020). Hence, one of the implications for services that may aim to deliver group START is to ensure group sizes remain within these limits. Other implications for services are available in Appendix G.

This study also adds to the increasing evidence base for the START programme. Quantitatively, there was some slight improvement in depression ratings but no change in anxiety, although this was not tested inferentially. Qualitatively, it appears that attending START was impactful, for example, by helping participants become more patient and reflective. This has also been observed in other studies evaluating START (Sommerlad et al., 2014). It appears that the principles and aims underpinning START can be implemented in a group setting.

Other experiences highlighted in this study have been demonstrated in other evaluations of START. Sommerlad and colleagues (2014), looking at the experiences of people who had completed the original START programme, found that the most reported helpful aspects included the impact of the START programme. For instance, participants gained more tolerance and felt validated about their feelings. Moreover, they found relational aspects helpful, such as receiving empathy and being able to share their concerns with the therapist. Finally, there was a desire to continually use things learned as part of the START programme, which included wanting a follow-up and seeking similar experiences in voluntary groups. Interestingly, like in the current study, participants reported few recommendations for improvement. Sommerlad and colleagues also highlighted that overall, there was heterogeneity in response to which aspects of START participants found helpful; this appeared to depend on the participant's unique needs, perhaps highlighting the need for an individualised approach in some cases. However, it also speaks to the strength of a multi-component intervention; that is, such an approach offers something that will be beneficial for each recipient.

Similar findings were reported in the 'START-online' evaluation (Loi et al., 2022), with participants reporting that helpful aspects included the importance of being able to share their concerns with a therapist and having ongoing support amidst isolation. However, here participants shared more about aspects they did not find helpful, particularly highlighting sections they found irrelevant to them, which may further suggest the utility of an individualised approach. It was also highlighted that caregivers found the intervention burdensome at times, which was also found in the current evaluation. This needs to be addressed in the future delivery of group START to avoid adding to the burden of caregivers as well as encourage participation. Nonetheless, START-online was deemed feasible and in the context of inclusion and increased demands, it may be worth considering offering and delivering START online as part of services.

Limitations

It was notable that participants were generally positive about their experiences doing group START. It is possible that using a focus group to evaluate their experiences

may have made participants more susceptible to wanting to please the research team. Moreover, it would be beneficial to see whether participants continued to use the information gained from group START in the long term and to have more voices or views in the interviews.

Although there was some insight into the feasibility and acceptability of group START, this process may have benefited from a detailed assessment approach. It has been suggested that acceptability includes assessing factors such as attitude towards intervention before the intervention and burden to perceived effectiveness post-intervention. Hence, it may not be appropriate to suggest that participants found the intervention universally acceptable without a more detailed evaluation of acceptability.

Similarly, using only the GAD-7 and the PHQ-9 limited our understanding of the experiences of participants, especially in capturing, quantitatively, other benefits that may be expected in such an intervention. Future evaluations of group START will benefit from, for instance, capturing possible therapeutic effects on quality of life (Daley et al., 2019) and caregiver sense of competence (Jansen et al., 2007). Moreover, although participants did not report experiencing any adverse effects in the focus groups, attempts to capture it quantitatively and anonymously may help highlight possible harms, especially that which may be unnoticed and unintended such as an increased sense of guilt, failure, and responsibility following attendance to group START (Roback, 2000).

The quantitative data was limited in that it was underpowered, analysed descriptively, and therefore having limited applicability to the general population. This means that the understanding gained about the impact of group START on mental health is limited. However, the use of qualitative methods has been useful in highlighting, and in some cases corroborating, some of the useful aspects of START that can often be missed by quantitative measures of effectiveness.

Methodologically, it may be that having one researcher may increase bias, limiting the richness of the qualitative analysis. Moreover, the analysis was not returned to participants for correction or comment, which could be argued as limiting the validity and richness of the findings. Finally, there is potential for a response bias because not all participants who attended the START group were present for the focus group. Indeed, all participants were at worst, moderately distressed, and level of distress may affect perceptions and use of the group.

Conclusions

This service evaluation looked at participants' experiences of doing group START in an NHS context as well as its preliminary impact on depression and anxiety. There is

some evidence that group START may be acceptable, meets the clinical and social needs of participants, and can be delivered in an NHS context. It also extends the evidence base for the START programme. A bigger, more powered evaluation would strengthen the rationale for use of group START in NHS settings, all in a bid to continue helping caregivers cope with the difficulty of dementia.

References

- Amador, S., Rapaport, P., Lang, I., Sommerlad, A., Mukadam, N., Stringer, A., . . . Livingston, G. (2021). Implementation of START (STrategies for RelaTives) for dementia carers in the third sector: Widening access to evidence-based interventions. *PLOS ONE*, *16*(6), e0250410. <https://doi.org/10.1371/journal.pone.0250410>
- Arvanitakis, Z., Shah, R. C., & Bennett, D. A. (2019). Diagnosis and management of dementia. *Jama*, *322*(16), 1589-1599.
- Biggs, K., Hind, D., Gossage-Worrall, R., Sprange, K., White, D., Wright, J., . . . Cooper, C. (2020). Challenges in the design, planning and implementation of trials evaluating group interventions. *Trials*, *21*(1), 116. <https://doi.org/10.1186/s13063-019-3807-4>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, *11*(4), 589-597.
- Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37-47.
- Braun, V., & Clarke, V. (2021b). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328-352. <https://doi.org/10.1080/14780887.2020.1769238>
- Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, *28*(6), 1942-1960. <https://doi.org/https://doi.org/10.1111/hsc.13048>
- Brody, H. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217-228.
- Chien, L.-Y., Chu, H., Guo, J.-L., Liao, Y.-M., Chang, L.-I., Chen, C.-H., & Chou, K.-R. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *International Journal of Geriatric Psychiatry*, *26*(10), 1089-1098. <https://doi.org/https://doi.org/10.1002/gps.2660>
- Craig, L. (2018). Service improvement in health care: a literature review. *Br J Nurs*, *27*(15), 893-896. <https://doi.org/10.12968/bjon.2018.27.15.893>
- Daley, S., Murray, J., Farina, N., Page, T. E., Brown, A., Basset, T., . . . Banerjee, S. (2019). Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. *Int J Geriatr Psychiatry*, *34*(1), 79-86. <https://doi.org/10.1002/gps.4990>
- Department of Health. (2015). *Prime Minister's Challenge on Dementia 2020*.

- Drew, J. R., & Pandit, M. (2020). Why healthcare leadership should embrace quality improvement. *BMJ*, 368, m872. <https://doi.org/10.1136/bmj.m872>
- Franchi, B. (2016). Pharmacological management of behavioural and psychological symptoms of dementia. *Pharmacy Practice and Research*, 46, 277–285.
- Gidron, Y. (2013). Group Therapy/Intervention. In M. D. Gellman & J. R. Turner (Eds.), *Encyclopedia of Behavioral Medicine* (pp. 880-881). Springer New York. https://doi.org/10.1007/978-1-4419-1005-9_1409
- Harding, R., Gao, W., Jackson, D., Pearson, C., Murray, J., & Higginson, I. J. (2015). Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia, and Acquired Brain Injury. *Journal of Pain and Symptom Management*, 50(4), 445--452.
- Hoddinott, P., Allan, K., Avenell, A., & Britten, J. (2010). Group interventions to improve health outcomes: a framework for their design and delivery. *BMC Public Health*, 10(1), 800. <https://doi.org/10.1186/1471-2458-10-800>
- Jansen, A. P., van Hout, H. P., van Marwijk, H. W., Nijpels, G., Gundy, C., Vernooij-Dassen, M. J., . . . Stalman, W. A. (2007). Sense of competence questionnaire among informal caregivers of older adults with dementia symptoms: a psychometric evaluation. *Clin Pract Epidemiol Ment Health*, 3, 11. <https://doi.org/10.1186/1745-0179-3-11>
- Kashimura, M., Rapaport, P., Nomura, T., Ishiwata, A., Tateno, A., Nogami, A., . . . Livingston, G. (2020). Acceptability and feasibility of a Japanese version of STrAtegies for RelaTives (START-J): A manualized coping strategy program for family caregivers of relatives living with dementia. *Dementia*, 20(3), 985-1004. <https://doi.org/10.1177/1471301220919938>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, 16(9), 606-613. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Laverentz, D. M., & Kumm, S. (2017). Concept evaluation using the PDSA cycle for continuous quality improvement. *Nursing Education Perspectives*, 38(5), 288-290.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer publishing company.
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., Romeo, R., . . . Cooper, C. (2014). START (STrAtegies for RelaTives) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia. *Health Technology Assessment*, 18(61).

- Livingston, G., Manela, M., O'Keffe, A., Rapaport, P., Cooper, C., Knapp, M., . . . Barber, J. (2019). Clinical effectiveness of the START (STrAtegies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with dementia: 6-year follow-up of a randomised controlled trial. *The British Journal of Psychiatry*(216), 35-42.
- Loi, S. M., Tropea, J., Gaffy, E., Panayiotou, A., Capon, H., Chiang, J., . . . Dow, B. (2022). START-online: acceptability and feasibility of an online intervention for carers of people living with dementia. *Pilot and Feasibility Studies*, 8(1), 41. <https://doi.org/10.1186/s40814-022-00999-0>
- Lyons, E., & Coyle, A. (2021). *Analysing qualitative data in psychology* (3rd edition. ed.). Los Angeles : SAGE.
- Malhotra, A., & Baker, J. (2022). Group Therapy. In *StatPearls*. StatPearls Publishing
- Copyright © 2022, StatPearls Publishing LLC.
- McCabe , M., You, E., & Tatangelo, G. (2016). Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. *The Gerontologist*, 56(5), 70-88.
- NHS Improvement. (2017). *Dementia assessment and improvement framework*.
- NICE. (2018). *Dementia: assessment, management and support for people living with dementia and their carers*. <https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>
- O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2016). Suicidal ideation in family carers of people with dementia. *Aging & Mental Health*, 20(2), 222-230.
- Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver Health: Health of Caregivers of Alzheimer's and Other Dementia Patients. *Current Psychiatry Reports*, 15(7), 367. <https://doi.org/10.1007/s11920-013-0367-2>
- Roback, H. B. (2000). Adverse outcomes in group psychotherapy: risk factors, prevention, and research directions. *J Psychother Pract Res*, 9(3), 113-122.
- Robinson, A. (2016). Advances in the prevention and treatment of dementia. *Prescriber*, 27(12), 18-24.
- Sachs, G. A. (2009). Dying from Dementia. *The New England Journal of Medicine*, 361, 1595-1596.
- Sommerlad, A., Manela, M., Cooper, C., Rapaport, P., & Livingston, G. (2014). START (STrAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. *BMJ Open*, 4(6), e005273. <https://doi.org/10.1136/bmjopen-2014-005273>

- Watts, S., Cheston, R., & Moniz-Cook, E. (2013). *An interim report prepared for the Faculty of Psychologists working with Older People and the Dementia Action Alliance*.
- Wittenberg, R., Hu, B., Jagger, C., Kingston, A., Knapp, M., Comas-Herrera, A., . . . Banerjee, S. (2020). Projections of care for older people with dementia in England: 2015 to 2040. *Age Ageing, 49*(2), 264-269. <https://doi.org/10.1093/ageing/afz154>
- Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., . . . Kingston, A. (2019). The costs of dementia in England. *The International Journal of Geriatric Psychiatry, 34*(7), 1095-1103.
- Wong, G., & Knapp, M. (2020). Should we move dementia research funding from a cure to its care? *Expert Review of Neurotherapeutics, 20*(4), 303-305. <https://doi.org/10.1080/14737175.2020.1735364>
- Xu, J., Zhang, Y., Qiu, C., & Cheng, F. (2017). Global and regional economic costs of dementia: a systematic review. *The Lancet, 390*, S47.
- Zwaanswijk, M., Peeters, J. M., van Beek, A. P., Meerveld, J. H., & Francke, A. L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The open nursing journal, 7*, 6-13. <https://doi.org/10.2174/1874434601307010006>

An exploratory study on the relationship between death and care attitudes in professionals working in dementia care

Benjamin Kwapong

Trainee Clinical Psychology (University of Bath)

bk513@bath.ac.uk

Main Research Project

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Internal supervisor: Dr Ashley Vanstone

External/field supervisor: Dr Anna Strudwick

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Proposed Journal: Death Studies (Word limit: not specified)

Rationale: This international journal publishes studies related to death, including death attitudes. It has a specific focus on those who work with the dying and their families.

Introduction

The Biomedical model and death anxiety

It is arguable that modern healthcare, including that for mental health problems, is influenced by the 'biomedical model' which aims to reduce or alleviate symptoms of physical illness and ultimately prolong life (Elkins, 2009). Within this model, the focus is on the illness and engaging in tasks that include managing medication and reducing risk to life (McKenzie et al., 2017; Stevens & Crouch, 1995). The biomedical model approach has led to many positive outcomes such as an increase in life expectancy and reductions in mortality (Jayachandran et al., 2010). However, a consequence has been the pursuit of prolonging life even when doing so is unlikely, costly, or distressing (Sallnow et al., 2022). At least in the Western world, death is perceived as an outcome that must be kept at bay for as long as possible, and this notion has been facilitated by advances in healthcare and the increasing responsibility of the healthcare system in dealing with death and the dying process (Gawande, 2014; Teno et al., 2013).

Modern attitudes and approaches to healthcare may be a manifestation of the uneasy reactions to death and mortality, which may be related to death anxiety (DA). DA has been defined in many ways, but it may be summarised as the unease, dread, or anxiety related to mortality, death, and dying, and is argued to be universal (Anderson & Heston, 2015; Arndt & Vess, 2008; Lehto & Stein, 2009). However, factors such as health status, age, experiences with death and dying, culture, and religion may influence one's attitude to death (Bluck et al., 2008; Iverach et al., 2014; Menzies & Veale, 2022; Yalom, 2008).

Much research has highlighted the link between DA and a range of human behaviours, including that observed as part of mental health conditions (Iverach et al., 2014). The literature has also demonstrated associations between DA and healthcare professionals' attitudes to care (Clare et al., 2020). For example, nurses with high DA have been observed to consistently have a negative attitude toward caring for the dying (Gurdogan et al., 2019; Peters et al., 2013). Nia et al. (2016) observed that high DA was associated with a range of 'negative' behaviours, including a decreased likelihood for social workers to discuss advance directives with other professionals (Black, 2007; Peck, 2009). For medical professionals, it has been found that higher DA was linked with greater difficulty in engaging with end-of-life communication (Draper et al., 2019) and those with higher DA were more likely to have a negative attitude towards palliative care (Thiemann et al., 2015). Similar findings have been observed for counsellors and nursing home employees (Neimeyer et al., 2004), although psychological professionals are generally under-represented.

Several theories address DA, and some have attempted to offer an account of the role of DA in human behaviour. Terror Management Theory (TMT) offers an explanation and, in the last four decades, has been the dominant theoretical lens through which DA and human behaviour have been explored. TMT provides an empirically tested, conscious and unconscious account of DA that explains a range of human behaviour and attitudes (Hoelterhoff, 2015). TMT builds on the work of Ernest Becker (Becker, 1973) and argues that the drive for self-preservation and the unique ability of being conscious of the inevitability of death raises terror which could be crippling in the absence of coping mechanisms (Greenberg et al., 1986; Pyszczynski et al., 2020). Humans have therefore developed ways of managing this terror (Arndt & Vess, 2008). According to the dual process model (Pyszczynski et al., 1999), how one copes with DA depends on whether reminders of death are in the conscious or unconscious mind. When conscious, one may engage the 'proximal defence', which involves removing thoughts of death from the conscious mind. Unconsciously, however, people cope with DA using 'distal defence', which involves boosting self-esteem by adhering to cultural worldviews which are a set of beliefs, attitudes, or behaviour that offers symbolic or literal immortality (Pyszczynski et al., 2015). TMT can perhaps explain why there is a preference to prolong life or prevent death in healthcare even when it is unhelpful because these preferences are consistent with the prevailing worldview in modern healthcare. Additionally, TMT offers an account of why healthcare professionals with higher DA may have negative attitudes toward the dying: those with terminal illnesses may be reminders of death and the imminent death threatens the dominant worldview. Much support has been generated for TMT through the examination of its hypotheses, including the mortality salience (MS) hypothesis, which argues that people rely on their defence mechanisms when mortality is experimentally made salient. Indeed, increasing MS leads to greater commitment to people's dominant worldview, which acts as a buffer for DA by boosting self-esteem and offering 'immortality' (Burke et al., 2010; Pyszczynski et al., 2015).

Person-centred and end-of-life care

In dementia care, person-centred care is the recommended approach, and it is often synonymous with "quality care" (Manthorpe & Samsi, 2016; McKeown et al., 2010; NICE, 2018). This approach involves engaging with individuals with dementia in a way that meets their psychosocial needs, in addition to meeting their biomedical needs (NICE, 2018). Person-centred care has been conceptualised in different ways, with Kitwood's (Kitwood, 1997) idea of "personhood" thought to be its foundation (Dewing, 2008; Fazio et al., 2018; Mitchell & Agnelli, 2015). *Personhood*, according to Kitwood, is the status given to people to acknowledge their "humanness" and person-centred care in dementia involves taking into account the person with dementia's personhood. Definitions of person-centred care

abound, but it may include – in addition to emphasising personhood – personalisation, involving people in their own care, providing choice, autonomy and providing an empowering environment (Edvardsson et al., 2010; Fazio et al., 2018). This approach to care has been associated with positive outcomes for staff and people living with dementia, including improvements in psychological wellbeing and reduction of stress (Ballard et al., 2018; Kim & Park, 2017).

Another recommended component of dementia care is discussing and planning end-of-life care, which might involve talking about death itself (Kumar & Kuriakose, 2013; NICE, 2018). End-of-life discussion and planning may be relevant at different paths within the healthcare system. For example, it may need to occur following diagnosis, which might involve the development of advance care plans including advance statements and advance directives. Indeed, it may be necessary amidst medical treatment for physical health conditions for the person living with dementia. There is evidence that patients and family members desire early end-of-life planning and that there are benefits to do so (Abba et al., 2013; Bamford et al., 2018). It may be especially important for end-of-life discussions to occur early for people with dementia as the progression of the disease means that they may be unable to make such decisions, thereby making the application of person-centred principles in end-of-life discussions difficult (Hegde & Ellajosyula, 2016).

Despite their importance for dementia care, both person-centred care and end-of-life planning are not implemented enough (Clare et al., 2020; Nicholson, 2020). Whilst many organisational and practical barriers may exist (Nicholson, 2020), clinicians might also face their own psychological barriers to engaging in person-centred care and embracing the challenges of facilitating end-of-life discussions and planning in a truly person-centred manner. The fear of death, or DA, may be one such barrier. DA is especially relevant in dementia care as exposure to older people with dementia – being reminders of mortality – has been found to trigger and increase levels of DA compared to older people who do not have dementia (McKenzie & Brown, 2017). Findings suggest that compared to younger people, older people in the workforce may be more susceptible to increases in DA levels given that they have more in common with the older person with dementia (Martens et al., 2005; O'Connor & McFadden, 2012) whereas younger people are able to psychologically distance themselves as dissimilar to older people with dementia (Cheston et al., 2020).

In relation to person-centred care, McKenzie et al. (2017) argue that healthcare professionals who score highly on DA cope with their fear of death by unconsciously favouring the biomedical approach, in line with TMT. This might include focusing on the biomedical needs of the person with dementia but also on administrative tasks associated

with the biomedical approach. However, McKenzie and colleagues also propose that experiential avoidance – or disengagement and avoidance of difficult inner experiences – may mediate the relationship between DA and person-centred care (Kitwood, 1997). As with many forms of anxiety, those with higher levels of DA may be more likely to rely on emotional disengagement as a coping mechanism (Hayes-Skelton & Eustis, 2020). Such disengagement allows for engagement with the biomedical approach but is incompatible with person-centred care (Kitwood, 1997; McKenzie et al., 2017).

Regarding end-of-life planning and discussions, DA has been qualitatively observed as one of the barriers to engagement in patients and healthcare professionals (Clare et al., 2020). Avoidance of end-of-life discussions and planning may further provide an opportunity to avoid difficult emotions and/or engage with other aspects of care that may fit with the dominant worldview. Indeed, engaging in end-of-life discussions has been recognised to be contrary to the biomedical approach to healthcare, where it remains taboo to discuss death (Margavio Striley et al., 2022). In sum, not engaging in end-of-life discussions might be a way of adhering to the dominant worldview.

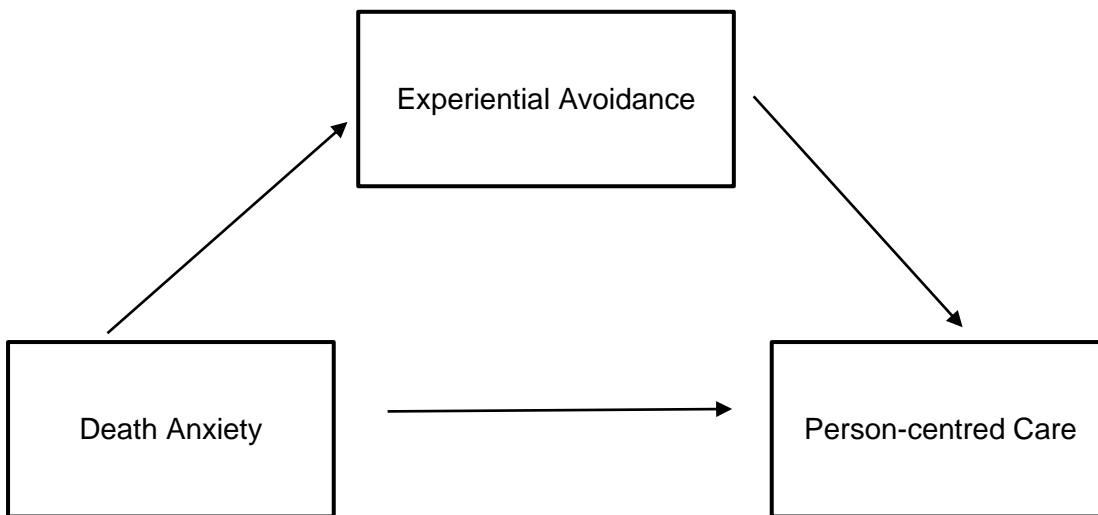
The current study

Despite the potential relationships outlined above, no study has explored these hypotheses. Therefore, the current study aims to investigate the relationship between DA, person-centred care attitudes and attitudes related to discussing death in healthcare professionals working with people with dementia. It also aims to explore whether there is a mediating role of experiential avoidance (see Figure 3.1). Findings here could contribute towards understanding and improving person-centred care and end-of-life conversations in clinical settings.

As the primary outcome, it was expected that clinician DA would predict person-centred care attitudes, with a negative relationship between the two. Experiential avoidance was expected to mediate this relationship. Furthermore, it was expected that clinician DA would predict attitudes to talking about death, with higher DA leading to more apprehensive attitudes toward discussing death.

Figure 3.1

Proposed model illustrating the relationship between DA, experiential avoidance and person-centred care attitudes.



Methods

Study design

This study used a survey design with the aim of capturing the views and attitudes of healthcare professionals in dementia care. Experts by experience were involved in all aspects of the design. Input came from people with personal experience of dementia care, people who have had personal experience of mental health, and clinical psychologists working in dementia care. An unpublished protocol was developed in partial fulfilment of requirements for the author’s Doctorate in Clinical Psychology.

Participants and Recruitment

Participants were required to be 18 years and above and engaged in paid employment as a healthcare professional working with people with dementia. Recruitment was primarily done online, using avenues such as Twitter, LinkedIn, MQ Mental Health Research, or via specialist professional groups such as the Faculty of Psychology for Older People (FPOP), and Memory Service Accreditation Programme (MSNAP). Other means of recruitment were through contacts in NHS services providing dementia care or healthcare training programmes with students working in dementia care. Participants were offered the opportunity to opt into a draw to win a voucher for their participation. 118 participants provided data for the research. For the primary outcome only, a minimum required sample size of 89 was determined using an a priori power analysis to achieve 95% power for detecting a medium-sized effect (.15) at alpha level .05.

Procedure and Study Materials

Participants were invited to complete the pack of questionnaires (see below) after reading the information sheet. They also provided demographic information such as their age, profession, years of experience, and training in person-centred care. Responses were all collected online via the Qualtrics survey software. The questionnaire was estimated to take between 10-15 minutes to complete and was opened between September 2022 to April 2023. The scales included in the study were:

The Collett-Lester Fear of Death Scale revised version 3 (CLFD-R; Lester & Abdel-Khalek, 2003). This is a 28-item scale measuring DA on four sub-scales: own death; own dying; death of others; and dying of others. The CLFD-R was used to measure DA. Participants respond to a number of statements by selecting how anxious or disturbed they to, for instance, “dying young” or “the pain involved in dying” on a 5-point Likert scale ranging from 5 (“very”) to 1 (“not”). Greater scores are interpreted as greater DA. Cronbach’s alpha for the four subscales ranged from .88 to .92 (Lester & Abdel-Khalek, 2003) and the overall Cronbach’s alpha for the sample in this study was .93 This scale has been demonstrated to be responsive to clinical change (Zuccala et al., 2019).

Brief Experiential Avoidance Questionnaire (BEAQ; Gámez et al., 2014). This is a 15-item questionnaire measuring experiential avoidance on a 6-point Likert scale (example items include “I feel disconnected with my emotions”). Higher scores on the BEAQ indicate higher experiential avoidance. The BEAQ has a Cronbach’s alpha of .80 (Gámez et al., 2014), and .88 in this sample. The BEAQ has also demonstrated concurrent validity as determined by associations with extant measures of avoidance and psychopathology (Gámez et al., 2014).

Patient-Practitioner Orientation Scale (PPOS; Krupat et al., 1999). The PPOS was used to measure attitudes to person-centred care. This 18-item questionnaire was developed for healthcare professionals and patients, assessing their beliefs of the extent to which healthcare professionals should share power and decision making with patients. An example Likert scale item is “a treatment plan cannot succeed if it is in conflict with a patient’s lifestyle or values”. The PPOS has demonstrated predictive validity, with greater scores shown to be associated with greater patient-centred behaviours in consultations (Shaw et al., 2012). It has also demonstrated sound internal consistency (Cronbach's alpha = .73) for healthcare professionals (Krupat et al., 2001), with a similar level of consistency (Cronbach's alpha = .81) in this sample.

Communication Apprehension About Death Scale (CADS; Carmack & DeGroot, 2015). The CADS was used to measure attitudes towards discussing matters related to

death and dying, thus as a proxy for likely engagement with end-of-life discussions. It is a 12-item, Likert scale measure with two dimensions: communication anxiety (example item, “I feel anxious talking about dying young”) and communication avoidance (example item, “I always try to not talk about death”). Responses for each item range from 1 (strongly disagree) to 5 (strongly agree). The CADS has sound reliability (Cronbach’s alpha = .93) with a similar level found in this sample (Cronbach’s alpha = .92). The CADS also demonstrated good concurrent validity, correlating positively with existing measures of DA and general communication anxiety (Carmack & DeGroot, 2015).

Ethics approval

This research was approved by the University of Bath research ethics committee (21-261).

Data Analysis

Statistical analyses were done using SPSS version 28. There were 118 participants overall, but 11 (9.3%) provided no data, and were subsequently removed from the analysis. The remaining 107 participants provided full responses for demographic information. 72% ($n = 85$) of the 118 participants provided complete responses, with no missing data for all four questionnaires. 11.6% ($n = 14$) had one to three questionnaires missing entirely, whilst 6.7% ($n = 8$) had missing data at item level only. Little’s missing completely at random (MCAR) test was conducted to assess the missing data pattern. The test confirmed that, for participants who contributed some data ($n = 107$), the data was missing completely at random ($\chi^2 = (1107) = 1108.13, p < .485$). The expectation maximisation method (Newman, 2014) was therefore used to impute missing values.

Descriptive statistics were calculated for participant demographic and outcome measures. A Pearson’s correlational analysis was conducted to examine the relationships between PPOS, CLFD-R, BEAQ and CADS. In line with the hypothesis, linear regression analyses were used to evaluate the extent to which CLFD-R scores predicted the PPOS, CADS, and the BEAQ. Regression analysis was also conducted to examine the extent to which scores on the BEAQ predicted scores on the PPOS. For the mediation analysis (Baron & Kenny, 1986), it was required that the independent variable predicts the dependent variable (direct effect). Moreover, the independent variable must predict the mediator and the mediator must subsequently predict the dependent variable (indirect effect). In this study, a mediation occurs when there is a significant indirect effect through the mediator, evidenced by the bootstrapped confidence intervals of the indirect effect not including 0 (Preacher & Hayes, 2004).

Results

Participant Characteristics

Descriptive statistics for participant characteristics are found in Table 3.1. Participants included practitioners from a broad age range ($M = 40.26$, $SD = 12.53$) and most were female. Participants mostly identified as White British and as having no religion. There was a range of professions represented, with nursing being the most frequently represented profession. In terms of setting, participants were mostly represented by community mental health teams. The majority of participants reported having had training in person-centred care. The mean years of professional experience was 15.24 ($SD = 12.31$) whilst the mean years of experience working with people with dementia was 11.58 years ($SD = 9.52$). The reported mean hours worked per week was 23.54 ($SD = 13.54$). The descriptive statistics for study variables in this sample are outlined in Table 3.1.

Correlational Analysis

Pearson's correlation coefficients are presented in Table 3.2. CLFD-R showed a positive correlation with the CADS; higher DA was associated with higher communication apprehension about death. CADS was positively associated with the BEAQ and negatively associated with PPOS, whilst the PPOS had a significant negative relationship with the BEAQ (see Table 3.2). Hence higher communication apprehension was associated with greater experiential avoidance and lower person-centred care attitudes, and higher experiential avoidance was associated with lower person-centred care attitudes.

Table 3.1*Descriptives for participant characteristics and study variables*

Variable	n (%)	M (SD; range)
total N	107	
Age		40.26 (12.53; 18-69)
Gender		
Male	17 (15.9)	
Female	89 (83.2)	
Non-binary	1 (0.9)	
Ethnicity		
White British	82 (76.6)	
White – Other	11 (10.3)	
Black or Black British	4 (3.7)	
Asian or Asian British	5 (4.7)	
Chinese	1 (0.9)	
Mixed Ethnicity	4 (3.7)	
Religious status		
Christian	30 (28)	
Hindu	3 (2.8)	
Jewish	1 (0.9)	
Muslim	2 (1.9)	
No religion	42 (39.3)	
Atheist/Agnostic	18 (16.8)	
Other	7 (6.5)	
Prefer not to say	4 (3.7)	
Profession		
Clinical Psychologist	11 (10.3)	
Assistant Psychologist	9 (8.4)	
Trainee Clinical Psychologist	8 (7.5)	
Occupational Therapist	7 (6.5)	
Healthcare Assistant	8 (7.5)	
Medical Doctor	5 (4.7)	
Medical Student	2 (1.9)	
Nurse	31 (29)	
Physiotherapist	2 (1.9)	
Other	24 (22.4)	
Setting		
Memory Clinic	10 (9.3)	

Variable	n (%)	M (SD; range)
Community Mental Health Team	28 (26.2)	
Ward	22 (20.6)	
General Hospital	9 (8.4)	
Care Home/Residential Care	9 (8.4)	
Charity	4 (3.7)	
Other	25 (23.4)	
Training in PCC		
Yes	94 (87.9)	
No	13 (12.1)	
Years of experience		15.24 (12.31; 1-45)
Years working with dementia		11.58 (9.52; 1-41)
Hours worked per <u>week</u>		23.54 (13.54; 1-49)
Measures		
CLFD-R		85.80 (19.59; 31-121)
BEAQ		43.54 (12.49; 17-77)
PPOS		83.79 (9.94; 42-102)
CADS		25.74 (8.32; 12-50)

Note. CLFD-R – The Collett-Lester Fear of Death Scale - revised version 3; BEAQ - Brief Experiential Avoidance Questionnaire; PPOS – Patient-Practitioner Orientation Scale; CADS – Communication Apprehension About Death Scale; PCC – Person-centred care

Table 3.2

Pearson's correlation between PPOS, BEAQ, CLFD-R and CADS

	1	2	3
1. CLFD – R			
2. BEAQ	.06		
3. PPOS	.10	-.34**	
4. CADS	.41**	.24*	-.32**

Note. CLFD-R – The Collett-Lester Fear of Death Scale - revised version 3; BEAQ - Brief Experiential Avoidance Questionnaire; PPOS – Patient-Practitioner Orientation Scale; CADS – Communication Apprehension About Death Scale. *Correlation is significant at .05 level.

**Correlation is significant at .01 level

Regression Analyses

In relation to the hypothesis, CLFD-R did not significantly predict PPOS ($R^2 = .10$, $F(1, 105) = 1.09$, $p = .298$) or BEAQ ($R^2 = .004$, $F(1, 105) = .424$, $p = .516$). However, CLFD-R significantly predicted CADS ($R^2 = .164$, $F(1, 105) = 20.60$, $p < .001$). BEAQ significantly predicted PPOS scores ($R^2 = .114$, $F(1, 105) = 13.49$, $p < .001$) (see

Table 3.3). Significant relationships between DA, person-centred care and experiential avoidance were a requirement for a mediation analysis to be conducted (see above). Therefore, the proposed mediation analysis was not undertaken.

Table 3.3

Summary of regression analyses

Predictors	PPOS			CADS			BEAQ		
	b	SE b	β	b	SE b	β	b	SE b	β
CLFD-R	.052	4.33	.102	.172	.038	.405	.040	.062	.063
BEAQ	-.268	.073	-.337						

Note. CLFD-R – The Collett-Lester Fear of Death Scale – revised version 3; BEAQ – Brief Experiential Avoidance Questionnaire; PPOS – Patient-Practitioner Orientation Scale; CADS – Communication Apprehension About Death Scale.

Discussion

Summary of findings

The current study aimed to investigate the relationship between DA, person-centred care attitudes, experiential avoidance, and attitudes about discussing death. Whilst DA was not significantly associated with person-centred care attitudes or experiential avoidance, levels of DA predicted apprehension in communicating about death; higher levels of DA were associated with higher levels of communication apprehension. Furthermore, experiential avoidance – the tendency towards disengagement and avoidance of unpleasant inner experiences – predicted person-centred care attitudes, such that participants with higher levels of experiential avoidance tended to endorse fewer attitudes characteristic of person-centred care. Higher levels of apprehension related to talking about death were associated with higher levels of experiential avoidance and lower levels of person-centred care.

Implications of findings

Whilst previous studies have suggested that DA is related to “negative” attitudes and behaviours amongst healthcare professionals (Nia et al., 2016; Peters et al., 2013), to the author’s knowledge, none had explored the relationship between DA and person-centred care. The failure to identify a direct association between DA and person-centred care runs contrary to the initial predictions and previous literature and suggests that healthcare professionals may not be unconsciously coping with DA by preferring the dominant biomedical model, therefore disengaging with person-centred care. Given the

ubiquity of DA and its high relevance in dementia care, this outcome may be interpreted as positive for the field. However, the correlational method used in this study may not fully delineate the relationship between DA, and its related construct mortality salience, and person-centred care. Given that contact with an older person with dementia can trigger mortality salience (McKenzie & Brown, 2017), an experimental approach in future studies could explore whether it is mortality salience rather than trait DA that impacts person-centred care attitudes and behaviours.

Nevertheless, what was consistent with previous research and predictions was the finding that DA was associated with attitudes toward discussing death (Black, 2007; Carmack & DeGroot, 2015; Draper et al., 2019), though the present study was the first to examine this association amongst clinicians in dementia care. In these contexts, discussing end-of-life, which may involve talking about death, is considered important (NICE, 2018) but such discussions may be against the dominant worldview in current healthcare settings. Therefore, healthcare professionals with higher DA may have greater scope to disengage with end-of-life communications in the current milieu. Additionally, these findings are even more significant considering that in these settings the patients are reminders of mortality, further adding to the possibility of disengagement. The impact and significance of DA on one's apprehension to discuss death could also apply to other settings where mortality is also salient, such as palliative care and oncology (Draper et al., 2019). Many factors are involved in facilitating end-of-life discussions, such as improving confidence in raising the topic (Margavio Striley et al., 2022) but given that DA is not often discussed openly (Menziez & Veale, 2022), the present findings suggest that clinicians' own DA should be considered in the design of initiatives or interventions to improve end-of-life-planning.

This study further adds to the evidence base by providing evidence that the tendency towards avoidance predicts person-centred care attitudes and that they are negatively associated (Kitwood, 1997; McKenzie et al., 2017). In addition, an increase in the tendency to experientially avoid was related to more apprehensive attitudes towards discussing death. These findings suggest that an avoidant approach could be an obstacle to fully adopting the attitudes of person-centred care and lead to increased disengagement with discussions about death. Despite the high proportion of participants reporting to have received training in person-centred care, there is evidence suggesting that training on person-centred care could be enhanced by raising awareness of the potential impact of clinicians' avoidance on the care they provide. Interventions aimed at improving person-centred care may also benefit from adopting techniques from Acceptance and Commitment Therapy (Harris, 2019), which can facilitate acceptance of difficult inner experiences and thereby reduce avoidance.

Strengths, limitations and future directions

The current study had sufficient statistical power and included participants from a range of professions, settings, experiences and ages. Therefore, the findings are expected to be reliable and applicable to clinicians across professions in which one may encounter those with dementia. This approach differs from that of the existing literature in this field, where the focus tends to be on a specific profession. Although this study was not designed to capture differences across professions, understanding differences between professions could yield insights into how the impact of DA could be mediated by factors such as professional training or clinical roles.

There were some limitations of the measures used. Whilst the PPOS has been widely adopted in measuring person-centred care, it overlooks an important facet, namely Kitwood's personhood (Mitchell & Agnelli, 2015). Future research may use other measures of person-centred attitudes such as the Approaches to Dementia Questionnaire (Lintern, 2001) but the current study was interested in attitudes related to person-centred care rather than attitudes towards a person with dementia and the PPOS was deemed to be more suitable for minimising response bias. All the extant measures of DA have some psychometric limitations (Zuccala et al., 2019), however, the CLFD-R and PPOS demonstrated good internal reliability and has been widely adopted in other research, thus facilitating comparison with previous research. The CLFD-R has the specific advantage of being sensitive to clinical change. More extensively validated and theoretically sound measures could facilitate a more precise understanding of the mechanisms underlying the relationship between DA and person-centred care. Future studies could adopt the Death Anxiety Beliefs and Behaviours Scale, which tackles the limitations of extant DA measures (Menziez et al., 2022).

The current study focused on attitudes of healthcare professionals rather than their behaviours. Whilst attitudes may not always translate to behaviour, there is evidence that attitudes can predict behaviour (Ajzen et al., 2018). In fact, in relation to person-centred care attitudes, the PPOS has been observed to predict behaviours aligned with person-centred care (Shaw et al., 2012). An advantage of exploring attitudes is that it is consistent with the literature and the approach to evaluation following training. Moreover, attitudes are the constant between healthcare professionals because behaviours, such as those related to person-centred care, may manifest differently within the different roles of healthcare professionals.

Conclusions

The current study found that DA was positively associated with attitudes to discussing death, and that one's tendency to avoid difficult experiences is negatively associated with person-centred attitudes. Hence, this study suggests that DA may be contributing to difficulties in initiating or engaging in end-of-life discussions and that avoidance may be negatively impacting person-centred care. The findings suggest that training on person-centred care and end-of-life communication, in addition to current approaches, should consider the underlying role of clinicians' own discomfort about the topic of death and could be supplemented by interventions to reduce avoidance and DA. There is a need for additional research on the other obstacles that prevent clinicians from having such discussions and taking approaches more aligned with person-centred care.

References

- Abba, K., Byrne, P., Horton, S., & Lloyd-Williams, M. (2013). Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them - a systematic literature review. *BMC Palliative Care*, 12(1), 40. <https://doi.org/10.1186/1472-684X-12-40>
- Ajzen, I., Fishbein, M., Lohmann, S., & Albarracín, D. (2018). The influence of attitudes on behavior. *The handbook of attitudes*, 197-255.
- Anderson, K. A., & Heston, J. L. (2015). Death Anxiety. In *The Encyclopedia of Adulthood and Aging* (pp. 1-4). <https://doi.org/https://doi.org/10.1002/9781118521373.wbeaa007>
- Arndt, J., & Vess, M. (2008). Tales from Existential Oceans: Terror Management Theory and How the Awareness of Our Mortality Affects Us All [https://doi.org/10.1111/j.1751-9004.2008.00079.x]. *Social and Personality Psychology Compass*, 2(2), 909-928. <https://doi.org/https://doi.org/10.1111/j.1751-9004.2008.00079.x>
- Ballard, C., Corbett, A., Orrell, M., Williams, G., Moniz-Cook, E., Romeo, R., . . . Fossey, J. (2018). Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. *PLoS Med*, 15(2), e1002500. <https://doi.org/10.1371/journal.pmed.1002500>
- Bamford, C., Lee, R., McLellan, E., Poole, M., Harrison-Dening, K., Hughes, J., . . . Exley, C. (2018). What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatrics*, 18(1), 302. <https://doi.org/10.1186/s12877-018-0983-0>
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of personality and social psychology*, 51, 1173-1182. <https://doi.org/10.1037/0022-3514.51.6.1173>
- Becker, E. (1973). *The denial of death*. Free Press.
- Black, K. (2007). Health care professionals' death attitudes, experiences, and advance directive communication behavior. *Death Studies*, 31(6), 563-572.
- Bluck, S., Dirk, J., Mackay, M. M., & Hux, A. (2008). Life Experience with Death: Relation to Death Attitudes and to the Use of Death-Related Memories. *Death Studies*, 32(6), 524-549. <https://doi.org/10.1080/07481180802138860>
- Burke, B. L., Martens, A., & Faucher, E. H. (2010). Two decades of terror management theory: a meta-analysis of mortality salience research. *Pers Soc Psychol Rev*, 14(2), 155-195. <https://doi.org/10.1177/1088868309352321>

- Carmack, H. J., & DeGroot, J. M. (2015). Development and Validation of the Communication Apprehension About Death Scale. *OMEGA - Journal of Death and Dying, 74*(2), 239-259. <https://doi.org/10.1177/0030222815598440>
- Cheston, R., Dodd, E., Christopher, G., White, P., Wildschut, T., & Sedikides, C. (2020). The Development and Validation of the Threat of Dementia Scale. *The International Journal of Aging and Human Development, 94*(4), 496-514. <https://doi.org/10.1177/0091415020957388>
- Clare, E., Elander, J., & Baraniak, A. (2020). How healthcare providers' own death anxiety influences their communication with patients in end-of-life care: A thematic analysis. *Death Studies, 1*-8. <https://doi.org/10.1080/07481187.2020.1837297>
- Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas [<https://doi.org/10.1111/j.1748-3743.2007.00103.x>]. *International Journal of Older People Nursing, 3*(1), 3-13. <https://doi.org/https://doi.org/10.1111/j.1748-3743.2007.00103.x>
- Draper, E. J., Hillen, M. A., Moors, M., Ket, J. C. F., van Laarhoven, H. W. M., & Henselmans, I. (2019). Relationship between physicians' death anxiety and medical communication and decision-making: A systematic review. *Patient Education and Counseling, 102*(2), 266-274. <https://doi.org/https://doi.org/10.1016/j.pec.2018.09.019>
- Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff [<https://doi.org/10.1111/j.1365-2702.2009.03143.x>]. *Journal of Clinical Nursing, 19*(17-18), 2611-2618. <https://doi.org/https://doi.org/10.1111/j.1365-2702.2009.03143.x>
- Elkins, D. N. (2009). The medical model in psychotherapy: Its limitations and failures. *Journal of Humanistic Psychology, 49*(1), 66-84.
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The Fundamentals of Person-Centered Care for Individuals With Dementia. *The Gerontologist, 58*(suppl_1), S10-S19. <https://doi.org/10.1093/geront/gnx122>
- Gámez, W., Chmielewski, M., Kotov, R., Ruggero, C., Suzuki, N., & Watson, D. (2014). The brief experiential avoidance questionnaire: development and initial validation. *Psychol Assess, 26*(1), 35-45. <https://doi.org/10.1037/a0034473>
- Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. Metropolitan Books.
- Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The Causes and Consequences of a Need for Self-Esteem: A Terror Management Theory. In R. F. Baumeister (Ed.),

Public Self and Private Self (pp. 189-212). Springer New York.

https://doi.org/10.1007/978-1-4613-9564-5_10

Gurdogan, E. P., Kinici, E., & Aksoy, B. (2019). The relationship between death anxiety and attitudes toward the care of dying patient in nursing students. *Psychology, Health & Medicine, 24*(7), 843-852.

Harris, R. (2019). *ACT made simple: An easy-to-read primer on acceptance and commitment therapy*. New Harbinger Publications.

Hayes-Skelton, S. A., & Eustis, E. H. (2020). Experiential avoidance. In *Clinical handbook of fear and anxiety: Maintenance processes and treatment mechanisms*. (pp. 115-131). American Psychological Association. <https://doi.org/10.1037/0000150-007>

Hegde, S., & Ellajosyula, R. (2016). Capacity issues and decision-making in dementia. *Ann Indian Acad Neurol, 19*(Suppl 1), S34-S39. <https://doi.org/10.4103/0972-2327.192890>

Hoelterhoff, M. (2015). A theoretical exploration of death anxiety. *Journal of Applied Psychology and Social Science, 1*(2), 1-17.

Iverach, L., Menzies, R. G., & Menzies, R. E. (2014). Death anxiety and its role in psychopathology: Reviewing the status of a transdiagnostic construct. *Clinical Psychology Review, 34*(7), 580-593.

<https://doi.org/https://doi.org/10.1016/j.cpr.2014.09.002>

Jayachandran, S., Lleras-Muney, A., & Smith, K. V. (2010). Modern Medicine and the Twentieth Century Decline in Mortality: Evidence on the Impact of Sulfa Drugs. *American Economic Journal: Applied Economics, 2*(2), 118-146.

<http://www.jstor.org/stable/25760208>

Kim, S. K., & Park, M. (2017). Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging, 12*, 381-397.

<https://doi.org/10.2147/cia.S117637>

Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first* (Vol. 20). Open university press Buckingham.

Krupat, E., Bell, R. A., Kravitz, R. L., Thom, D., & Azari, R. (2001). When physicians and patients think alike: patient-centered beliefs and their impact on satisfaction and trust. *J Fam Pract, 50*(12), 1057-1062.

Krupat, E., Hiam, C. M., Fleming, M. Z., & Freeman, P. (1999). Patient-Centeredness and its Correlates among First Year Medical Students. *The International Journal of Psychiatry in Medicine, 29*(3), 347-356. <https://doi.org/10.2190/DVCQ-4LC8-NT7H-KE0L>

NT7H-KE0L

- Kumar, C. S., & Kuriakose, J. R. (2013). End-of-life care issues in advanced dementia. *Mental health in family medicine, 10*(3), 129-132.
<https://pubmed.ncbi.nlm.nih.gov/24427179>
- Lehto, R. H., & Stein, K. F. (2009). Death anxiety: an analysis of an evolving concept. *Res Theory Nurs Pract, 23*(1), 23-41. <https://doi.org/10.1891/1541-6577.23.1.23>
- Lester, D., & Abdel-Khalek, A. (2003). The Collett-Lester fear of death scale: A correction. *Death Studies, 27*(1), 81-85.
- Lintern, T. C. (2001). Quality in dementia care : evaluating staff attitudes and behaviour.
- Manthorpe, J., & Samsi, K. (2016). Person-centered dementia care: current perspectives. *Clinical interventions in aging, 17*33-1740.
- Margavio Striley, K., Tenzek, K. E., & Field-Springer, K. (2022). Difficult dialogues about death: applying risk orders theory to analyse chaplains' provision of end-of-life care. *Health, Risk & Society, 24*(3-4), 167-185.
<https://doi.org/10.1080/13698575.2022.2056582>
- Martens, A., Goldenberg, J. L., & Greenberg, J. (2005). A Terror Management Perspective on Ageism. *Journal of Social Issues, 61*(2), 223-239.
<https://doi.org/https://doi.org/10.1111/j.1540-4560.2005.00403.x>
- McKenzie, E. L., & Brown, P. M. (2017). Nursing students' death anxiety and fear towards dementia patients. *Australas J Ageing, 36*(3), E32-E35.
<https://doi.org/10.1111/ajag.12414>
- McKenzie, E. L., Brown, P. M., Mak, A. S., & Chamberlain, P. (2017). 'Old and ill': death anxiety and coping strategies influencing health professionals' well-being and dementia care. *Aging Ment Health, 21*(6), 634-641.
<https://doi.org/10.1080/13607863.2016.1144711>
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing, 5*(2), 148-158.
<https://doi.org/https://doi.org/10.1111/j.1748-3743.2010.00219.x>
- Menzies, R. E., Sharpe, L., & Dar-Nimrod, I. (2022). The development and validation of the Death Anxiety Beliefs and Behaviours Scale. *British Journal of Clinical Psychology, 61*(4), 1169-1187. <https://doi.org/https://doi.org/10.1111/bjc.12387>
- Menzies, R. E., & Veale, D. (2022). *Free yourself from death anxiety : a CBT self-help guide for a fear of death and dying*. London : Jessica Kingsley Publishers.
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nurs Stand, 30*(7), 46-50. <https://doi.org/10.7748/ns.30.7.46.s47>

- Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: an overview and evaluation. *Death Stud*, 28(4), 309-340.
<https://doi.org/10.1080/07481180490432324>
- Newman, D. A. (2014). Missing Data: Five Practical Guidelines. *Organizational Research Methods*, 17(4), 372-411. <https://doi.org/10.1177/1094428114548590>
- Nia, H. S., Lehto, R. H., Ebadi, A., & Peyrovi, H. (2016). Death Anxiety among Nurses and Health Care Professionals: A Review Article. *International journal of community based nursing and midwifery*, 4(1), 2-10.
<https://pubmed.ncbi.nlm.nih.gov/26793726>
- NICE. (2018). *Dementia: assessment, management and support for people living with dementia and their carers*.
<https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>
- Nicholson, L. (2020). Achieving person-centred dementia care through a bio-psychosocial model. *Nursing Times [online]*, 117(1), 50-53.
- O'Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults' Ageism and Attitudes Toward Dementia. *Educational Gerontology*, 38(9), 627-643. <https://doi.org/10.1080/03601277.2011.595335>
- Peck, M. R. (2009). Personal Death Anxiety and Communication About Advance Directives Among Oncology Social Workers. *Journal of Social Work in End-of-Life & Palliative Care*, 5(1-2), 49-60. <https://doi.org/10.1080/15524250903173892>
- Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., . . . Shimoinaba, K. (2013). How death anxiety impacts nurses' caring for patients at the end of life: a review of literature. *The open nursing journal*, 7, 14-21.
<https://doi.org/10.2174/1874434601307010014>
- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers*, 36(4), 717-731. <https://doi.org/10.3758/BF03206553>
- Pyszczynski, T., Greenberg, J., & Solomon, S. (1999). A dual-process model of defense against conscious and unconscious death-related thoughts: An extension of terror management theory. *Psychological Review*, 106(4), 835-845.
<https://doi.org/10.1037/0033-295X.106.4.835>
- Pyszczynski, T., Lockett, M., Greenberg, J., & Solomon, S. (2020). Terror Management Theory and the COVID-19 Pandemic. *Journal of Humanistic Psychology*, 61(2), 173-189. <https://doi.org/10.1177/0022167820959488>

- Pyszczynski, T., Solomon, S., & Greenberg, J. (2015). Chapter One - Thirty Years of Terror Management Theory: From Genesis to Revelation. In J. M. Olson & M. P. Zanna (Eds.), *Advances in Experimental Social Psychology* (Vol. 52, pp. 1-70). Academic Press. <https://doi.org/https://doi.org/10.1016/bs.aesp.2015.03.001>
- Sallnow, L., Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C., Cong, Y., . . . Wyatt, K. (2022). Report of the Lancet Commission on the Value of Death: bringing death back into life. *Lancet (London, England)*, 399(10327), 837-884. [https://doi.org/10.1016/s0140-6736\(21\)02314-x](https://doi.org/10.1016/s0140-6736(21)02314-x)
- Shaw, W. S., Woiszwilllo, M. J., & Krupat, E. (2012). Further validation of the Patient-Practitioner Orientation Scale (PPOS) from recorded visits for back pain. *Patient Education and Counseling*, 89(2), 288-291. <https://doi.org/https://doi.org/10.1016/j.pec.2012.07.017>
- Stevens, J., & Crouch, M. (1995). Who cares about care in nursing education? *International Journal of Nursing Studies*, 32(3), 233-242. [https://doi.org/https://doi.org/10.1016/0020-7489\(95\)00002-F](https://doi.org/https://doi.org/10.1016/0020-7489(95)00002-F)
- Teno, J. M., Gozalo, P. L., Bynum, J. P., Leland, N. E., Miller, S. C., Morden, N. E., . . . Mor, V. (2013). Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Jama*, 309(5), 470-477. <https://doi.org/10.1001/jama.2012.207624>
- Thiemann, P., Quince, T., Benson, J., Wood, D., & Barclay, S. (2015). Medical Students' Death Anxiety: Severity and Association With Psychological Health and Attitudes Toward Palliative Care. *Journal of Pain and Symptom Management*, 50(3), 335-342.e332. <https://doi.org/https://doi.org/10.1016/j.jpainsymman.2015.03.014>
- Yalom, I. D. (2008). *Staring at the sun : overcoming the terror of death*. San Francisco : Jossey-Bass.
- Zuccala, M., Menzies, R. E., Hunt, C. J., & Abbott, M. J. (2019). A systematic review of the psychometric properties of death anxiety self-report measures. *Death Studies*, 46(2), 1-23. <https://doi.org/10.1080/07481187.2019.1699203>

Executive Summary

The research papers in this portfolio may differ, but they share themes, including the exploration of the role of death attitudes in mental health conditions and the care of people with neurological conditions by staff and those outside of healthcare services. The collective aim for these projects was to contribute to improving care for two conditions, namely obsessive-compulsive disorder and dementia, which can be challenging for staff, family members and the individuals living with them.

Literature review

Given the inevitability of death and the human drive to survive, social and psychological theorists have argued that humans have a fear of death which underlies human behaviour. Terror management theory is one such theory. Here, it is argued that one way of coping with the fear of death is to remove it from conscious awareness but generally, when the fear of death is outside awareness, people cope by engaging in activities or holding onto belief that offers them immortality. Sometimes, however, this way of coping is inadequate, and other forms of coping may be used. It is argued that mental health difficulties, especially those with themes related to the prevention of death such as some forms of obsessive-compulsive disorder, may be driven by the fear of death. If this is the case, then it has implications for our understanding of such mental health problems and their treatment. Whilst there is some evidence for this, a formal, unbiased review of the available evidence has not been done so far. The current review sought to do this and searched the literature in a systematic way to ensure all available literature is captured. The literature reviewed showed that the more someone feared death, the worse their OCD severity and their general psychological well-being. Moreover, reminding people of death increased their OCD behaviours. Finally, the higher one's fear of death, the more they were likely to develop other anxiety disorders before developing OCD. These studies suggest that, at least, clinical treatment of OCD should begin to explore and if needed, treat the fear of death. However, there is more to be done. For example, future studies should explore whether these findings apply to other age groups with OCD, such as children and young people or older adults.

Service-related project

As life expectancy increases, the number of people living with dementia is expected to rise along with it. Although there have been improvements in the care of people with dementia over the last 30 years, a cure is yet to be found. Those who care for people living with dementia at home, such as friends, family, and spouses, are invaluable, yet this can be challenging both physically and emotionally. It is therefore important to

develop ways of helping them cope with the challenges of providing care for someone living with dementia. The STrAtegies for RelaTives (START) programme was developed for this purpose and it has been demonstrated to help reduce low mood and anxiety in caregivers when delivered individually. However, it had not been evaluated in group form. We wanted to evaluate caregivers' experiences of doing the START programme when delivered in a group setting within a mental health service in the NHS.

Four (out of six) people who had attended the group shared their thoughts as part of a focus group. We also measured their ratings of low mood and anxiety each week whilst doing group START. There were some indications that attending the group reduced feelings of low mood but feelings of anxiety, already low, remained unchanged. Participants shared how being part of a group allowed them to share feelings with people who understood and being part of a group helped them learn from others in a similar situation. They also mentioned tangible benefits from the group, which included encouragement to prioritise taking care of themselves. Overall, they found the group a positive experience but suggested that it could also be improved. This evaluation highlighted that group START fits well with the aims and principles of the individual START programme and could be a potentially useful service provision for caregivers. However, it will require more research to increase confidence in using group START routinely.

Main research project

Person-centred care, which may be understood as care that takes into consideration of the individual's wishes and personalised needs, is the recommended approach in dementia care. Despite this, there are many potential barriers to healthcare professionals providing care that is consistent with this approach. The barriers may be psychological, and it has been suggested that healthcare professionals' discomfort with death, or death anxiety (DA), may get in the way of engaging with person-centred care. Furthermore, clinician DA may also impact their willingness to engage in end-of-life discussions and planning, which is another important component of dementia care. The impact of DA has not yet been explored in healthcare professionals working in dementia care. This study aimed to look at whether DA impacted person-centred care attitudes and attitudes to discussing death. It also aimed to explore whether the tendency to avoid difficult emotions played a role in person-centred care attitudes. A range of participants from varying professional backgrounds completed questionnaires looking at DA, attitudes to person-centred care, tendency to avoid difficult emotions, and attitudes to discussing death. The study found that DA predicted attitudes to discussing death such that an increase in death anxiety was related to higher apprehension towards talking about death. Moreover, a

tendency towards avoidance of difficult emotions and experiences was related to lower levels of person-centred care attitudes. The result of this study suggests that clinician discomfort about death and ways of coping could be playing a role in their care and should be considered in training aiming to improve person-centred care and end-of-life discussions.

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I have not forgotten the help received from the wider clinical doctorate and admin team. Your responsiveness is commendable, and you helped ease a challenging process. I would also want to thank the rest of Cohort 2020, the unofficial 'Covid cohort', whose support made the process enjoyable. Thanks especially for the socials, which definitely helped keep things in perspective. I hope to stay in touch and look forward to seeing everyone flourish on their respective paths.

Last, but not the least, many thanks go to my dear family, far and near. Your understanding, patience, prayers, encouragement was instrumental in making all this possible. I look forward to celebrating my success with you!

Appendices

Appendix A

LR: Summary of Search Strategy

Development of basic search terms using the following keywords: “fear of death” OR “fear of dying” OR thanatophob* OR “attitudes to death” OR “attitudes towards dying” OR “attitudes toward dying” OR “existential fear” OR “existentialist fear” OR “death anx*” OR “death fear” OR “mortality salien*” AND “obsessive compulsive disorder*” OR “OCD” OR compuls*

(eventual) search strategy for each database

Database	Search terms/strategy	Fields that search will be conducted e.g., Title, abstract, Author keywords.	Date, Time and Results
Psychinfo	(((title: ("mortality salien*")) OR ((abstract: ("mortality salien*")) OR (kw: ("mortality salien*")) OR ((title: ("death fear")) OR ((abstract: ("death fear")) OR (kw: ("death fear")) OR ((title: ("death anx*")) OR ((abstract: ("death anx*")) OR (kw: ("death anx*")) OR ((title: ("existential fear")) OR ((abstract: ("existential fear")) OR (kw: ("existential fear")) OR ((title: ("attitudes toward dying")) OR ((abstract: ("attitudes toward dying")) OR (kw: ("attitudes toward dying")) OR ((title: ("attitudes towards death")) OR ((abstract: ("attitudes towards death")) OR (kw: ("attitudes towards death")) OR ((title: ("attitudes to death")) OR ((abstract: ("attitudes to death")) OR (kw: ("attitudes to death")) OR ((title: ("fear of dying")) OR ((abstract: ("fear of dying")) OR (kw: ("fear of dying")) OR ((title: (thanatophob*)) OR ((abstract: (thanatophob*)) OR (kw: (thanatophob*)) OR ((title: ("fear of dying")) OR ((abstract: ("fear of dying")) AND (kw: ("fear of dying")) OR ((title: ("fear of death")) OR ((abstract: ("fear of death")) OR (kw: ("fear of	Title, abstract, author, keywords	7.7.2022 at 4.42 pm 46 results Rerun on 8.7.2022 at 4.40 and results was 44

	death")))) AND (((title: (compuls*)) OR ((abstract: (compuls*)) OR (kw: (compuls*)) OR (((title: ("obsessive compulsive disorder*")) OR ((abstract: ("obsessive compulsive disorder*")) OR (kw: ("obsessive compulsive disorder*")) OR (((title: (OCD)) OR ((abstract: (ocd)) OR (kw: (ocd))))		
SCOPUS	((TITLE-ABS-KEY ("mortality salien*")) OR (TITLE-ABS-KEY ("death fear")) OR (TITLE-ABS-KEY ("death anx*")) OR (TITLE-ABS-KEY ("fear of death")) OR (TITLE-ABS-KEY ("fear of dying")) OR (TITLE-ABS-KEY (thanatophob*)) OR (TITLE-ABS-KEY ("attitudes towards dying")) OR (TITLE-ABS-KEY ("attitudes to death")) OR (TITLE-ABS-KEY ("attitudes toward dying")) OR (TITLE-ABS-KEY ("existential fear"))) AND ((TITLE-ABS-KEY (compuls*)) OR (TITLE-ABS-KEY ("obsessive compulsive disorder*")) OR (TITLE-ABS-KEY ("ocd"))))	Title, Abstract, Keywords	7.7.2022 at 3.02pm 90 results
Web of Science Core Collection	Basic search terms 17. #16 AND #15 16. #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 15. #13 OR #12 OR #14 14. compuls* (Topic) 13."OCD" (Topic) 12. "obsessive compulsive disorder*" 11. "mortality salien*" (Topic) 10. "death fear" (Topic) 9. "death anx*" (Topic) 8. "existentialist fear" (Topic) 7. "existential fear" (Topic) 6. "attitudes toward dying" (Topic) 5. "attitudes towards dying" (Topic) 4. "attitudes to death" (Topic) 3. "thanatophob*" (Topic) 2. "fear of dying" (Topic) 1. "fear of death" (Topic)	Title, abstract, author, keywords and keywords plus.	7.7.2022 at 12.58pm Results – 38 papers.

PubMed	((("ocd"[Title/Abstract] OR "obsessive compulsive disorder*"[Title/Abstract] OR "compuls*"[Title/Abstract]) AND "fear of death"[Title/Abstract]) OR "fear of dying"[Title/Abstract] OR "thanatophob*"[Title/Abstract] OR "attitudes to death"[Title/Abstract] OR "existential fear"[Title/Abstract] OR "death anx*"[Title/Abstract] OR "death fear"[Title/Abstract] OR "mortality salien*"[Title/Abstract])	7.7.2022 at 3.32pm Results 1,663
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Total, with duplicates removed – 1770

Dates searched 7th and 8th July 2022

Appendix B

LR: Data Extraction Table

Title, Authors, Country and Year	Aims	Characteristics: Participants	Methods: Methodology Design Variables and Measures	Brief Description of Procedure	Key Findings	Conflicts of Interest	Funding

Appendix C

LR: Quality Ratings for Each Study

	Theoretical underpinning.	Statement of research aim/s.	Description of setting/sample.	Appropriate study design.	Appropriate sampling.	Rationale for choice of tools.	Appropriate data collection tools.	Description of procedure.	Recruitment data provided.	Justification for analytic method.	Appropriate analysis	Stakeholders considered.	Strengths/limitations discussed.
Strachan et al. (2007)	Green	Amber	Green	Green	Red	Red	Green	Green	Red	Red	Green	Red	Red
Enjedani and Khodapanahi (2011)	Amber	Amber	Amber	Green	Red	Red	Red	Amber	Red	Red	Green	Red	Red
Fergus and Valentiner (2012)	Green	Green	Amber	Green	Red	Amber	Green	Green	Red	Green	Green	Red	Green
Menzies and Dar-Nimrod (2017) Study 1	Green	Red	Green	Green	Green	Red	Green	Red	Amber	Red	Green	Red	Red
Menzies and Dar-Nimrod (2017) Study 2	Green	Red	Green	Green	Green	Red	Green	Red	Amber	Amber	Green	Red	Red
Menzies et al. (2019)	Green	Green	Green	Green	Green	Green	Green	Amber	Green	Amber	Green	Red	Amber
Menzies et al. (2020) Study 1	Amber	Amber	Green	Green	Green	Amber	Green	Red	Amber	Red	Green	Red	Green
Menzies et al. (2020) Study 2	Amber	Amber	Green	Green	Green	Amber	Green	Red	Amber	Red	Amber	Red	Green
Menzies et al. (2021)	Green	Green	Green	Green	Amber	Amber	Green	Red	Amber	Amber	Green	Red	Amber
Chawla et al. (2022)	Amber	Green	Green	Green	Green	Green	Green	Amber	Amber	Amber	Green	Red	Green
Verin et al. (2022)	Green	Green	Green	Green	Green	Amber	Green	Amber	Green	Amber	Green	Red	Green

Note: Each criterion is scored on 0 – 3. Red denotes a score of 0/1; Amber denotes a score of 2; Green denotes a score of 3.

Appendix D

LR: QuADS Criteria

QuADS Criteria	0	1	2	3
1. Theoretical or conceptual underpinning to the research	No mention at all.	General reference to broad theories or concepts that frame the study. e.g. key concepts were identified in the introduction section.	Identification of specific theories or concepts that frame the study and how these informed the work undertaken. e.g. key concepts were identified in the introduction section and applied to the study.	Explicit discussion of the theories or concepts that inform the study, with application of the theory or concept evident through the design, materials and outcomes explored. e.g. key concepts were identified in the introduction section and the application apparent in each element of the study design.
2. Statement of research aim/s	No mention at all.	Reference to what the sought to achieve embedded within the report but no explicit aims statement.	Aims statement made but may only appear in the abstract or be lacking detail.	Explicit and detailed statement of aim/s in the main body of report.
3. Clear description of research setting and target population	No mention at all.	General description of research area but not of the specific research environment e.g. 'in primary care.'	Description of research setting is made but is lacking detail e.g. 'in primary care practices in region [x]'. Specific description of the research setting and target population of study e.g. 'nurses and doctors from GP practices in [x] part of [x] city in [x] country.'	
4. The study design is appropriate to address the stated research aim/s	No research aim/s stated or the design is entirely unsuitable e.g. a Y/N item survey for a study seeking to undertake exploratory work of lived experiences. .	The study design can only address some aspects of the stated research aim/s e.g. use of focus groups to capture data regarding the frequency and experience of a disease.	The study design can address the stated research aim/s but there is a more suitable alternative that could have been used or used in addition e.g. addition of a qualitative or	The study design selected appears to be the most suitable approach to attempt to answer the stated research aim/s.

			quantitative component could strengthen the design.	
5. Appropriate sampling to address the research aim/s	No mention of the sampling approach.	Evidence of consideration of the sample required e.g., the sample characteristics are described and appear appropriate to address the research aim/s.	Evidence of consideration of sample required to address the aim. e.g. the sample characteristics are described with reference to the aim/s.	Detailed evidence of consideration of the sample required to address the research aim/s. e.g. sample size calculation or discussion of an iterative sampling process with reference to the research aims or the case selected for study.
6. Rationale for choice of data collection tool/s	No mention of rationale for data collection tool used.	Very limited explanation for choice of data collection tool/s. e.g. based on availability of tool.	Basic explanation of rationale for choice of data collection tool/s. e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool/s. e.g., relevance to the study aim/s, co-designed with the target population or assessments of tool quality.
7. The format and content of data collection tool is appropriate to address the stated research aim/s	No research aim/s stated and/or data collection tool not detailed.	Structure and/or content of tool/s suitable to address some aspects of the research aim/s or to address the aim/s superficially e.g. single item response that is very general or an open-response item to capture content which requires probing.	Structure and/or content of tool/s allow for data to be gathered broadly addressing the stated aim/s but could benefit from refinement. e.g. the framing of survey or interview questions are too broad or focused to one element of the research aim/s.	Structure and content of tool/s allow for detailed data to be gathered around all relevant issues required to address the stated research aim/s.
8. Description of data collection procedure	No mention of the data collection procedure.	Basic and brief outline of data collection procedure e.g. 'using a questionnaire distributed to staff.'	States each stage of data collection procedure but with limited detail or states some stages in detail but	Detailed description of each stage of the data collection procedure, including when, where and how

9. Recruitment data provided			omits others e.g. the recruitment process is mentioned but lacks important details.	data was gathered such that the procedure could be replicated.
	No mention of recruitment data.	Minimal and basic recruitment data e.g. number of people invited who agreed to take part.	Some recruitment data but not a complete account e.g., number of people who were invited and agreed.	Complete data allowing for full picture of recruitment outcomes e.g., number of people approached, recruited, and who completed with attrition data explained where relevant.
10. Justification for analytic method selected	No mention of the rationale for the analytic method chosen.	Very limited justification for choice of analytic method selected. e.g. previous use by the research team.	Basic justification for choice of analytic method selected e.g., method used in prior similar research.	Detailed justification for choice of analytic method selected e.g., relevance to the study aim/s or comment around of the strengths of the method selected.
11. The method of analysis was appropriate to answer the research aim/s	No mention at all.	Method of analysis can only address the research aim/s basically or broadly.	Method of analysis can address the research aim/s but there is a more suitable alternative that could have been used or used in addition to offer a stronger analysis.	Method of analysis selected is the most suitable approach to attempt answer the research aim/s in detail e.g. for qualitative interpretative phenomenological analysis might be considered preferable for experiences vs. content analysis to elicit frequency of occurrence of events.
12. Evidence that the research stakeholders have been considered in research design or conduct.	No mention at all.	Consideration of some the research stakeholders e.g. use of pilot study with target sample but no	Evidence of stakeholder input informing the research. e.g. use of pilot study with feedback influencing the study	Substantial consultation with stakeholders identifiable in planning of study design and in preliminary work e.g., consultation in the

13. Strengths and limitations critically discussed		stakeholder involvement in planning stages of study design.	design/conduct or reference to a project reference group established to guide the research.	conceptualisation of the research, a project advisory group or evidence of stakeholder input informing the work.
	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues. <u>e.g.</u> one or two strengths/limitations mentioned with limited detail.	Discussion of some of the key strengths and weaknesses of the study but not complete. <u>e.g.</u> several strengths/limitations explored but with notable omissions or lack of depth of explanation.	Thorough discussion of strengths and limitations of all aspects of study including design, methods, data collection tools, sample & analytic approach.

Appendix E

LR: PRISMA-ScR Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use,	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	

Appendix F

LR: Relevant Author Guidelines, Journal of Obsessive-Compulsive and Related Disorders

Submissions Type:

The journal of obsessive-compulsive and related disorders accepts systematic literature reviews related to OCD.

Manuscript must include keywords, figures and tables. Citations of figures and tables must match.

World limits are presented for shorter communications/brief reports only, where there is a limit of 3000-5000 words.

Ethics (informed consent and patient details):

Studies on patients or volunteers require ethics committee approval and informed consent, which should be documented in the paper. Appropriate consents, permissions and releases must be obtained where an author wishes to include case details or other personal information or images of patients and any other individuals in an Elsevier publication. Written consents must be retained by the author but copies should not be provided to the journal. Only if specifically requested by the journal in exceptional circumstances (for example if a legal issue arises) the author must provide copies of the consents or evidence that such consents have been obtained. For more information, please review the Elsevier Policy on the Use of Images or Personal Information of Patients or other Individuals. Unless you have written permission from the patient (or, where applicable, the next of kin), the personal details of any patient included in any part of the article and in any supplementary materials (including all illustrations and videos) must be removed before submission.

Use of generative AI in scientific writing:

The below guidance only refers to the writing process, and not to the use of AI tools to analyse and draw insights from data as part of the research process. Where authors use generative artificial intelligence (AI) and AI-assisted technologies in the writing process, authors should only use these technologies to improve readability and language. Applying the technology should be done with human oversight and control, and authors should carefully review and edit the result, as AI can generate authoritative-sounding output that can be incorrect, incomplete or biased. AI and AI-assisted technologies should not be listed as an author or co-author, or be cited as an author. Authorship implies responsibilities and tasks that can only be attributed to and performed by humans, as outlined in Elsevier's AI policy for authors. Authors should disclose in their manuscript the use of AI and AI-assisted technologies in the writing process by following the instructions below. A statement will appear in the published work. Please note that authors are ultimately responsible and accountable for the contents of the work.

Use of inclusive language:

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang,

reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Reporting of Systematic Reviews:

For systematic reviews and meta-analysis the journal recommends following the PRISMA guidelines (<http://www.prisma-statement.org/>)(<http://www.prisma-statement.org/>).

Article Structure:

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results. If the focus of the paper is on a disorder other than OCD (as defined in DSM-IV.TR), provide a rationale for including the disorder as an obsessive-compulsive related disorder (see Editorial Guidance section).

Methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described. Theory/calculation A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature. Be sure to include limitations of the present study and suggestions for future research.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Abstract:

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Keywords:

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Tables:

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References:*Citation in text*

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference formatting

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/ book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Appendix G

SRP: Recommendations for service and rationale

Recommendation	Rationale
Continue to support carers with Group START	There is evidence from the group that it is effective and acceptable. Its core structure meets NICE guidelines, and NICE's recommendations for supporting carers of people with dementia suggest making support available in a group setting. However, opportunities to tailor support then becomes limited because of the resources and nature of the group.
Provide resources and/or information pack with key information and contacts that participant can access in between sessions	Participants spoke about this being missing from their experience of the group. This may reduce the reported sense of isolation and helplessness. It is also recommended by NICE guidelines.
Continue to provide space for participants to share experiences during group START	This was a key feature of participants' experience of group START, especially as they reported feeling isolated and felt they did not have the opportunity to speak about their experiences elsewhere. Having the space to share and feel understood may reduce feelings of isolation.
Utilise carer expertise	Participants valued hearing from each other (linked to above) and learning implicitly from each other's experiences. Other Later Life services have invited carers who have previously attended support groups, and participants have reported this to be the most useful aspect of the group.
Informal follow-up group for carers with dementia	Participants recommended this so that they could continue to benefit from the group's support. This may involve supporting participants to initiate groups but maintained by them going forward.

	Doing so may increase carer resilience, thereby impacting carer anxiety and depression and furthering connection with services.
Maintain smaller groups	Participants felt this allowed them to build stronger relationships and gave them space to express themselves. It has been suggested that the ideal group sizes for intervention may be between 5 to 10 (Biggs et al., 2020).
Collecting anonymous feedback and/or use an external researcher	Participants provided a very positive view of the intervention, and it may be useful to see whether their views may have changed had they provided anonymous feedback. Alternatively, participants could provide anonymous feedback on a session-by-session basis.
Follow up research of next iteration of group START	Getting a range of participants to share their experiences may yield broader perspectives. Group START may also be delivered online given current changes in the delivery of services and this too could be evaluated. Recent research suggests that online delivery of START is acceptable and feasible (Loi et al., 2021).

Results and recommendations were initially shared with the psychology lead for the local NHS trust, L.C., and another psychologist, K.S., who were both involved in the development of the group (on 22.3.2021). The following ideas and steps were discussed/agreed upon:

- To share the information with wider stakeholders, including members from IAPT team, local organisations, and staff who are involved in providing care and support for caregivers.
- To potentially change the name of the third theme as this may mislead people, e.g., by removing the (lack of) at least in the presentation slide.

Appendix H

SRP: Trust Approval

Dear Benjamin

RE: Anxiety and Depression Group Service Evaluation
Local Ref: 21/039/GHCSE

Thank you for sending your updated proposal through. This email confirms approval for the above study on behalf of Gloucestershire Health and Care NHS Foundation Trust.

Thank you again for your help and patience as we worked out the issues around consent for this study.

If you have any questions about this approval, please let me know.

Kind regards

Mark

Mark Walker
Head of Research and Development
Gloucestershire Health and Care NHS Foundation Trust

Pronouns: He/Him

Appendix I

SRP: Relevant Author Guidelines, Qualitative Health Research

Submissions Type:

- QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.
- Read the Mission Statement on main QHR webpage.
- Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta- analyses, and articles addressing all qualitative methods.
- QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.
- QHR does NOT publish pilot studies.

Each issue of Qualitative Health Research provides readers with a wealth of information —, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

Abstracts should be 250 words or less, and Original Research Articles should be 6,000 words or less excluding the abstract and list of references

Preparing your manuscript for submission:

4.1 Article Format (see previously published articles in QHR for style):

- Blinding: A version of the manuscript which has had any information that compromises the anonymity of the author(s) removed or anonymized. This version **will** be sent to peer reviewers.
- Title page: Title should be succinct; list all authors and their affiliation; keywords. Include any removed or anonymized material. Please upload the title page separately from the main document. This **will not** be sent to the peer reviewers.
- Blinding: Do not include any author identifying information in your manuscript. See <https://sagepub.com/Manuscript-preparation-four-double-blind-journal> for detailed guidance on making an anonymous submission.

- Abstract: Maximum of 250 words. This should be the first page of the main manuscript, and it should be on its own page. Please ensure the abstract is unstructured i.e. no sub-headings.
- Length: Original Research Articles should be 6,000 words or less excluding the abstract and references. Manuscripts should be as tight as possible.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor’s Preferences:

Authors should not include qualitative research checklists, such as COREQ (COnsolidated criteria for REporting Qualitative research), within their manuscripts. Based on the specific qualitative methodology and/or methods, it may be appropriate for authors to describe steps, activities, or concepts related to rigor. For additional information on this policy, please read [Why the Qualitative Health Research \(QHR\) Review Process Does Not Use Checklists](#)

Please do not refer to your manuscript as a “paper;” you are submitting an “article.”

The word “data” is plural.

Appendix J

MRP: Participant Information Sheet and Debrief Sheet

Participant Information Sheet

Title of Project: A study exploring attitudes to death and approaches to care

Researcher name: Ben Kwapong

Purpose and benefit of the research:

This study aims to look at attitudes to death and care amongst healthcare professionals working with people with dementia. The project aims to recruit approximately 89 participants in the UK. We hope to better understand factors related to caring for those living with dementia.

What would taking part involve?

The study will involve completing a survey which will include providing demographic information and four questionnaires. This should take approximately 15-20 minutes.

You will be given the opportunity to provide your email address for a chance to be entered into a draw to win a £50 Amazon voucher, if you wish. Email address entries are stored separately from the survey results to ensure your data remains anonymous.

What are the possible disadvantages and risks of taking part?

It is anticipated that the completion of the survey will not present any risks or harm to participants greater than those encountered in everyday life. However, if you feel uncomfortable answering questions, you can request to pass that item. If you do become distressed by engaging in the study, you may contact the researcher and/or supervisor (details below). Alternatively, you may contact:

- Samaritans (Telephone: 116 123; 24 hours a day)
- Mind Infoline (Telephone: 0300 123 3393; 9am-6pm; Monday to Friday or text 86463)
- Rethink Mental Illness Advice Line (Telephone: 0300 5000 927; 9.30am - 4pm; Monday to Friday)

What will happen if I don't want to carry on with the study?

Participation in this study is completely voluntary. If you do decide to take part but change your mind during the study, you may end your participation at any time by closing the browser. You do not have to provide a reason for this. You can withdraw from the study up until the point of submitting your survey response because of anonymity of the data.

What will happen to my data?

Confidentiality: Only the researcher/s will have access to the individual information provided by participants. Privacy and confidentiality will always be assured. The research outcomes may be presented at conferences, written up for publication and shared with patient, public and professional groups. However, in all these publications, the privacy and confidentiality of individuals will be protected.

Anonymity: All reports and publications of the research will contain no information that can identify any individual and all information will be kept in the strictest confidence.

Storage: The information collected will be stored securely on a password protected drive on the University of Bath server throughout the project. It will then be stored at the University of Bath for a required period of 10 years before being destroyed as per university protocols.

What will happen to the results of this study?

The results will be written up for partial fulfilment of the DClinPsy course at the University of Bath. It may also be published and disseminated in academic publications, conferences, and to the stakeholders of UK DClinPsy courses, such as clinical psychologists, DClinPsy trainers, trainee clinical psychologists and policy makers.

Ethical approval

This project has received ethical approval from the Psychology Research Ethics Committee: Ref number: 21-261

Queries or concerns may be directed to the researcher and/or supervisor (details below).

Further information and contact details

If you would like further information or would like to discuss any details, please get in touch with either the researcher and/or supervisor:

Benjamin Kwapong (researcher)
Trainee Clinical Psychologist
10 West
University of Bath
Claverton Down
Bath
BA2 7AY
Email: bk513@bath.ac.uk

Dr Ashley Vanstone (supervisor)
Clinical Psychologist and Lecturer
10 West
University of Bath
Claverton Down
Bath
BA2 7AY
Email: adv30@bath.ac.uk

Queries and concerns

If you have any other concerns related to your participation in this study please direct them to the Chair of the Department of Psychology Research Ethics Committee, email: psychology-ethics@bath.ac.uk

Ref Number: 21-261

Please click 'proceed to study' to continue. If you do not wish to proceed, please exit the survey now.

Debrief Sheet

Title of Project: Exploring the relationship between death anxiety, communicating about death and person-centred care attitudes in healthcare professionals working with people with dementia.

Thank you for taking time out to complete this study. Please see below for more information about the project.

Background and Rationale

There are indications that death anxiety, which refers to fear of death, dying and what happens in the afterlife, can impact attitudes in healthcare provision.

In dementia care, person-centred care is the recommended approach, and it has been suggested that many factors may impact the attitudes and provision of person-centred including death anxiety. Levels of death anxiety may also impact discussions about death and end-of-life.

The present study aims to investigate the relationship between levels of death anxiety and person-centred care attitudes in healthcare professionals working with people with dementia. It also aims to look at whether emotional avoidance plays a role in this relationship. Finally, it explores the relationship between death anxiety levels and communication about death and dying.

This study will help establish the theoretical understanding of the impact of death anxiety on the care of people with dementia, which may lead to a number of outcomes, including potential interventions for healthcare professionals.

What happened in the study?

You were asked to provide demographic details which would help establish the nature of the relationship between death anxiety and person-centred care. The questionnaires you completed measured your levels of death anxiety, fear of communicating about death, attitudes towards person-centred care and your level of engagement with difficult feelings and emotions.

Further Support

We understand from previous studies that there is little risk of emotional distress when completing questionnaires about death anxiety. However, if you have in any way been affected by this study, please contact the researcher and/or the supervisor (contact details below). In the meantime, you can access the following sources of support:

- Samaritans (Telephone: 116 123; 24 hours a day)
- Mind Infoline (Telephone: 0300 123 3393; 9am-6pm; Monday to Friday or text 86463)
- Rethink Mental Illness Advice Line (Telephone: 0300 5000 927; 9.30am - 4pm; Monday to Friday)

Further information and contact details

If you would like further information or would like to discuss any details, please get in touch with either the research and/or supervisor:

Benjamin Kwapong (researcher)
Trainee Clinical Psychologist
10 West
University of Bath
Claverton Down
Bath
BA2 7AY
Email: bk513@bath.ac.uk

Dr Ashley Vanstone (supervisor)
Clinical Psychologist and Lecturer
10 West
University of Bath
Claverton Down
Bath
BA2 7AY
Email: adv30@bath.ac.uk

If you have any other concerns related to your participation in this study please direct them to the Chair of the Department of Psychology Research Ethics Committee, email: psychology-ethics@bath.ac.uk

Ref Number: 21-261

Please enter your email address if you would like to be entered into a prize draw for your participation

Appendix K

MRP: Ethics Approval Confirmation

FW: 21-261



psychology-ethics
To: Benjamin Kwapong
Cc: psychology-ethics

You forwarded this message on 01/06/2022 14:20.



PREC full application form BK V4 with amendments.pdf
986 KB



Application Form for an Amendment BK 21-261.docx
309 KB

Hi Ben,

I have reviewed your replies and am taking Chairs Action to approve the application. Good luck with the research.

Best wishes,
Chris Ashwin
Chair of PREC

PARTICIPANTS WANTED!

Exploring attitudes about death and approaches to dementia care

Department of Psychology



UNIVERSITY OF BATH



Ethics Code:

PREC: 21-261

ARE YOU A HEALTHCARE PROFESSIONAL
WORKING WITH PEOPLE WITH DEMENTIA?

If yes, we would like to invite you to complete a survey about approaches to care.

You will be asked to anonymously complete some questionnaires online. This should take about 15-20 minutes.

You will have a chance to be entered in a draw to win a £50 amazon voucher.

Interested? Please scan QR code above or use the link below:

tinyurl.com/44kpps77

CONTACT

Ben Kwamong

Clinical Psychologist in Training
bk513@bath.ac.uk
(researcher)

Dr Ashley Vanstone

Clinical Psychologist
adv30@bath.ac.uk
(supervisor)

Appendix M

MRP: Questionnaires

The Collett-Lester Fear of Death scale – revised version 3

The Collett–Lester Fear of Death Scale Version 3.0

How disturbed or made anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Don't spend too much time thinking about your response. We want your first impression of how you think right now. Circle the number that best represents your feeling.

	Very	Somewhat	Not		
Your Own Death					
1. The total isolation of death	5	4	3	2	1
2. The shortness of life	5	4	3	2	1
3. Missing out on so much after you die	5	4	3	2	1
4. Dying young	5	4	3	2	1
5. How it will feel to be dead	5	4	3	2	1
6. Never thinking or experiencing anything again	5	4	3	2	1
7. The disintegration of your body after you die	5	4	3	2	1
Your Own Dying					
1. The physical degeneration involved	5	4	3	2	1
2. The pain involved in dying	5	4	3	2	1
3. The intellectual degeneration of old age	5	4	3	2	1
4. That your abilities will be limited as you lay dying	5	4	3	2	1
5. The uncertainty as to how bravely you will face the process of dying	5	4	3	2	1
6. Your lack of control over the process of dying	5	4	3	2	1
7. The possibility of dying in a hospital away from friends and family	5	4	3	2	1
The Death of Others					
1. Losing someone close to you	5	4	3	2	1
2. Having to see the person's dead body	5	4	3	2	1
3. Never being able to communicate with the person again	5	4	3	2	1
4. Regret over not being nicer to the person when he or she was alive	5	4	3	2	1
5. Growing old alone without the person	5	4	3	2	1
6. Feeling guilty that you are relieved that the person is dead	5	4	3	2	1
7. Feeling lonely without the person	5	4	3	2	1

APPENDIX *(Continued)*

	Very	Somewhat	Not		
The Dying of Others					
1. Having to be with someone who is dying	5	4	3	2	1
2. Having the person want to talk about death with you	5	4	3	2	1
3. Watching the person suffer from pain	5	4	3	2	1
4. Seeing the physical degeneration of the person's body	5	4	3	2	1
5. Not knowing what to do about your grief at losing the person when you are with him or her	5	4	3	2	1
6. Watching the deterioration of the person's mental abilities	5	4	3	2	1
7. Being reminded that you are going to go through the experience also one day	5	4	3	2	1

Scoring: The circled scores are summed for each 7-item subscale.

Communication Apprehension About Death Scale (CADS)

Table 2. Communication Apprehension About Death Scale Items.

- | |
|--|
| Q1. I feel anxious talking about never thinking or experiencing anything again. (CANX) |
| Q2. I feel anxious talking about how it will feel to be dead. (CANX) |
| Q3. I feel anxious talking about the shortness of life. (CANX) |
| Q4. I feel anxious talking about the fact that I am going to die one day. (CANX) |
| Q5. I feel anxious talking about dying young. (CANX) |
| Q6. I feel anxious talking about the total isolation of death. (CANX) |
| Q7. I avoid talking about death altogether. (CAV) |
| Q8. I avoid talking about death at all costs. (CAV) |
| Q9. I have an intense fear of talking about death. (CAV) |
| Q10. I always try to not talk about death. (CAV) |
| Q11. I am tense and nervous while participating in discussions about death. (CAV) |
| Q12. I am tense and nervous while discussing death. (CAV) |

Brief Experiential Avoidance Questionnaire (BEAQ)

Please indicate the extent to which you agree or disagree with each of the following statements

1	2	3	4	5	6
strongly disagree	moderately disagree	slightly disagree	slightly agree	moderately agree	strongly agree

- | | | | | | | | |
|-----|---|---|---|---|---|---|---|
| 1. | The key to a good life is never feeling any pain | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. | I'm quick to leave any situation that makes me feel uneasy | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. | When unpleasant memories come to me, I try to put them out of my mind | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. | I feel disconnected from my emotions | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. | I won't do something until I absolutely have to | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. | Fear or anxiety won't stop me from doing something important | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. | I would give up a lot not to feel bad | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. | I rarely do something if there is a chance that it will upset me | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. | It's hard for me to know what I'm feeling | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. | I try to put off unpleasant tasks for as long as possible | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. | I go out of my way to avoid uncomfortable situations | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. | One of my big goals is to be free from painful emotions | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. | I work hard to keep out upsetting feelings | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. | If I have any doubts about doing something, I just won't do it | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. | Pain always leads to suffering | 1 | 2 | 3 | 4 | 5 | 6 |

Patient-Practitioner Orientation Scale (PPOS)

		1	2	3	4	5	6
1.	The doctor is the one who should decide what gets talked about during a visit. <i>El médico es el que debería decidir de que es lo que se habla durante una visita.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	Although health care is less personal these days, this is a small price to pay for medical advances. <i>Aunque hoy en día el cuidado médico es menos personal, esto es un precio pequeño que pagar por todos los adelantos (de la medicina).</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	The most important part of the standard medical visit is the physical exam. <i>La parte más importante de una visita médica regular (estándar, corriente) es el examen físico.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Version 1.05 08/09/2004



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PPO



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SITE: 01 - 00 PART ID: RELATION: ASSESS DATE: / /

		Strongly Disagree <i>Muy en Desacuerdo</i>	Moderately Disagree <i>Moderadamente en desacuerdo</i>	Slightly Disagree <i>Un poco en desacuerdo</i>	Slightly Agree <i>Un poco de acuerdo</i>	Moderately Agree <i>Moderadamente de acuerdo</i>	Strongly Agree <i>Muy de acuerdo</i>
		1	2	3	4	5	6
4.	It is often best for patients if they do not have a full explanation of their medical condition. <i>A menudo, es mejor para los pacientes si no reciben una explicación completa de su condición médica.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	Patients should rely on their doctors' knowledge and not try to find out about their conditions on their own. <i>Los pacientes deberían confiar en el conocimiento de sus médicos y no tratar de informarse acerca de sus condiciones por sus propios medios.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	When doctors ask a lot of questions about a patient's background, they are prying too much into personal matters. <i>Cuando los médicos hacen muchas preguntas sobre los</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7.	If doctors are truly good at diagnosis and treatment, the way they relate to patients is not that important. <i>Si los médicos son verdaderamente buenos en el diagnóstico y el tratamiento, la manera como se relacionan con el paciente no es tan importante.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8.	Many patients continue asking questions even though they are not learning anything new. <i>Muchos pacientes continúan haciendo preguntas aun cuando ne están aprendiendo nada nuevo.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Version 1.05 08/09/200



Healthy Families Program
PPO

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SITE: - PART ID: RELATION: - ASSESS DATE: ___/___/___

		Strongly Disagree <i>Muy en Desacuerdo</i>	Moderately Disagree <i>Moderadamente en desacuerdo</i>	Slightly Disagree <i>Un poco en desacuerdo</i>	Slightly Agree <i>Un poco de acuerdo</i>	Moderately Agree <i>Moderadamente de acuerdo</i>	Strongly Agree <i>Muy de acuerdo</i>
		1	2	3	4	5	6
9.	Patients should be treated as if they were partners with the doctor, equal in power and status. <i>Los pacientes deberían ser tratados como si fueran socios del médico, igual en posición (estado) y poder.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10.	Patients generally want reassurance rather than information about their health. <i>En vez de información sobre su salud los pacientes generalmente quieren que los reaseguren.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
11.	If a doctor's primary tools are being open and warm, the doctor will not have a lot of success. <i>Si los instrumentos principales del médico son el ser abierto y cálido, el médico no tendrá mucho éxito.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
12.	When patients disagree with their doctor, this is a sign that the doctor does not have the patient's respect and trust. <i>Cuando los pacientes están en desacuerdo con sus médico, esta es una señal que el médico no tiene el respeto ni la confianza del paciente.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

13.	A treatment plan cannot succeed if it is in conflict with a patient's lifestyle or values. <i>Un plan de tratamiento no puede tener éxito si está en conflicto con el estilo de vida o los valores del paciente.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	Most patients want to get in and get out of the doctor's office as quickly as possible. <i>La mayoría de los pacientes quieren entrar y salir de la oficina del médico lo más rápido posible.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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		Strongly Disagree <i>Muy en Desacuerdo</i>	Moderately Disagree <i>Moderadamente en desacuerdo</i>	Slightly Disagree <i>Un poco en desacuerdo</i>	Slightly Agree <i>Un poco de acuerdo</i>	Moderately Agree <i>Moderadamente de acuerdo</i>	Strongly Agree <i>Muy de acuerdo</i>
		1	2	3	4	5	6
15.	The patient must always be aware that the doctor is in charge. <i>El paciente debe estar siempre consciente de que el médico es el que esta a cargo.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	It is not that important to know a patient's culture and background in order to treat the person's illness. <i>No es tan importante conocer la cultura y los antecedentes del paciente para tratar la enfermedad de la persona.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	Humor is a major ingredient in the doctor's treatment of the patient. <i>El humor es un ingrediente importante en el tratamiento que provee el médico al paciente.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18.	When patients look up medical information on their own, this usually confuses more than it helps. <i>Cuando los pacientes buscan información por su cuenta, esto usualmente confunde más que ayuda.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix N

MRP: Author Guidelines, Death Studies

Article Types

Full-length research articles or reviews of the literature and brief reports

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should contain an unstructured abstract of 150 words.
- Should contain between 3 and 5 **keywords**.

Title

Use bold for your article title, with an initial capital letter for any proper nouns.

Abstract

Indicate the abstract paragraph with a heading or by reducing the font size.

Reference Style: APA-7

Headings

This will show you the different levels of the heading section in your article:

1. First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.
2. Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
3. Third-level headings should be in italics, with an initial capital letter for any proper nouns.
4. Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.
5. Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Formatting and Templates

Though exceptions can be made for methodologically complex studies, it is suggested that full-length articles not exceed 25 pages, including abstract, references, tables, and figures. Brief reports are encouraged and should be no longer than 15 pages.