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**Caring for older people: insights from trainee clinical psychologists
and family carers**

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This thesis is submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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List of abbreviations

AA	African Americans
BME	Black and Minority Ethnic
BPS	British Psychological Society
BRCOPE	Brief Religious Coping Scale
BIS	Burden Interview Scale
CES-D	Centre for Epidemiological Studies – Depression Scale
DCP	Division of Clinical Psychology
EBLIP	Evidence Based Library and Information Practice
FPOP	The Faculty of Psychology of Older People
GDS	Geriatric Depression Scale
HCPC	Health and Care Professions Council
IPA	Interpretative Phenomenological Analysis
LA	Latino Americans
MMSE	Mini Mental State Examination
NICE	National Institute for Health and Clinical Excellence
OA	Older Adult
ONS	Office for National Statistics
OPPES	Older Persons Pleasant Events Scale
PAC	Positive Aspects of Caregiving
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSIGE	Psychologists’ Special Interest Group for the Elderly
REACH	Resources for Enhancing Alzheimer’s Caregiver Health

SEM	Structural Equation Model
UK	United Kingdom
USA	United States of America
WA	White Americans
WHO	World Health Organisation
ZBI	Zarit Burden Interview

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Declaration

This thesis has not been submitted for any other degree or to any other institution. It was conducted under the academic supervision of Dr Tom Patterson (Academic Director of the Coventry and Warwick Clinical Psychology Doctorate) and the clinical supervision of Jane Muers (Clinical Psychologist). Both supervisors helped me to develop my initial research ideas and provided suggestions and feedback throughout. One of my colleagues and both of my supervisors, all familiar with Interpretative Phenomenological Analysis, were involved in validating my coding. Apart from these collaborations, this thesis is my own work.

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Chapter 3: 3,561

TOTAL: 18,906

Summary

This thesis focuses on the care of older people, both those with and without dementia, by family caregivers and one group of health professionals (trainee clinical psychologists). This thesis considers and explores a number of factors which are important to those providing care. These factors have been defined specifically as Religion / Spirituality in the literature review, which focuses on family caregivers of people with dementia. However, in the empirical paper those factors important to providing care were not pre-defined by the research team but emerged from the data. It is hoped that, in conjunction, these papers will contribute to understanding the perspectives of those caring for older people.

Chapter 1 is a systematic literature review investigating the association between religion/spirituality and the psychological wellbeing/role adjustment among Black and Minority Ethnic (BME) family (informal) dementia caregivers. It focuses on one specific factor 'religion/spirituality' in order to understand one aspect of the dementia caregiving experience.

Chapter 2 is an empirical study exploring trainee clinical psychologists' experiences of working with older people, including people with and without dementia. Interpretative phenomenological analysis (IPA) was used to analyse the transcript data from eight interviews with participants. Three superordinate themes and nine subordinate themes emerged following the data analysis. The themes are explored, including implications for research, clinical practice and clinical psychology doctoral training.

Chapter 3 is a reflective account, which includes the experience of carrying out the research and the insights it provided. Adopting the theme of 'story' allowed a connection to be made between hearing the stories of older people, and hearing the stories of participants in IPA research. The theme of 'story' then also allowed further exploration of this topic in books, research and media articles.

Chapter One: Literature Review

A systematic review of the role of religion/spirituality in the psychological wellbeing/role adjustment of Black and Minority Ethnic (BME) informal dementia caregivers.

In preparation for submission to *Dementia* (see Appendix A for Author Instructions)

Overall chapter word count (excluding tables, figures, footnotes and references): 7,803

1.1 Abstract

The aim of the present literature review was to critically evaluate the empirical evidence investigating the association between religion/spirituality and psychological wellbeing/role adjustment among Black and Minority Ethnic (BME) informal dementia caregivers. A search of the literature, including databases and citations, identified fifteen studies, all from the USA, for inclusion in the present review. These were critically evaluated using a quality assessment tool and the findings of the studies were summarised. Religion and spirituality were found to be important factors to consider among BME dementia caregivers. They were associated with reduced caregiver burden and increased reports of positive aspects of caregiving. There was an inconsistent association between religion/spirituality and reduced depression. Clinical implications include the need to train those supporting BME dementia caregivers with religious and spiritual beliefs, so that their needs can be assessed and interventions adapted accordingly. The review implications are limited by the inclusion of studies from the USA only. Further research should aim to use consistent measures to assess religion/spirituality with clearly defined constructs, so that comparisons between studies can be made.

1.2 Introduction

1.2.1 Dementia caregiving

Dementia is *“a progressive and largely irreversible clinical syndrome that is characterised by widespread impairment of mental function”* (National Institute for Health and Clinical Excellence, NICE, 2006, p. 4). People with dementia are affected by a number of difficulties, including memory loss and often require support in activities of daily living, relying upon close relatives or friends to provide care for them at home. There are an estimated 670,000 of such unpaid informal caregivers in the United Kingdom (UK; Alzheimer’s Society, 2012). Caring for someone with dementia has the potential to have more marked adverse effects on those family members providing care, than caring for someone with a different medical diagnosis. For example, Clipp and George (1993) found that dementia caregivers’ wellbeing was worse than cancer caregivers’ wellbeing, and suggest that cognitive and behavioural problems may explain this discrepancy.

1.2.2 Black and Minority Ethnic (BME) dementia caregiving

Within the total figure of informal carers in the UK, an increasing proportion come from a Black and Minority Ethnic (BME)¹ background. There are an estimated 25,000 BME people with dementia in the UK currently, with a seven-fold increase predicted within the next 40 years, compared to an anticipated two-fold increase in the dementia population overall (All Party Parliamentary Group on Dementia, 2013). The discrepancy is due to increasing

¹ The BME population is defined as the population from all ethnic groups with the exception of White British. White Irish, Indian, Pakistani, Chinese and Black Caribbean are large ethnic minority communities amongst older people in the UK (All Party Parliamentary Group on Dementia, 2013).

immigration to the UK from the 1950s onwards (Office for National Statistics, 2011). The Republic of Ireland, India, Pakistan and Jamaica, are among the top ten countries from which people emigrated; and those who remained as UK residents are now ageing (Office for National Statistics, 2011). In multicultural Britain, it is increasingly important to understand the diversity of dementia caregiving experiences. A better understanding of the needs of carers may enable service providers to improve access and create culturally sensitive caregiver interventions.

1.2.3 Religion and spirituality in dementia caregiving

Religious coping has been identified as beneficial for dementia caregivers (Acton & Miller, 2003). Religion and spirituality represent another aspect of diversity within populations, the role of which is important to understand. People from across ethnic groups differ in their religious and spiritual beliefs and practices, including affiliation to religious faiths and participation in religious activities. Informal caregivers' beliefs may influence their experience of caregiving. Religion and spirituality have been found to help informal carers to find meaning (Quinn, Clare & Woods, 2012) and cope with the challenges of the role. Dementia caregivers identifying with a particular religion have been found to report benefits of religion and spirituality as coping resources (Stuckey, 2003).

1.2.4 Religion and spirituality in BME dementia caregivers

Religion and spirituality are also one way of exploring the experiences of BME communities. Qualitative studies have identified benefits of religion and spirituality for BME dementia caregivers (Farran, Paun & Elliott, 2003; Toth-Cohen, 2004). Regan (2014) argues that it is important to distinguish religion and spirituality from the concept of 'culture', which may be too loosely defined. The specific aspects of religion and spirituality on dementia care pathways among the BME population in the UK formed the focus of a

recent literature review (Regan, Bhattacharyya, Kevern & Rana, 2013). However, the review identified only two studies which addressed the topic, both in the United States of America (USA). The findings suggested that religion assists in positive coping and makes it less likely that caregivers will use traditional health care pathways.

1.2.5 Psychological wellbeing of dementia caregivers

Social and health services' budgets do not have capacity to provide residential dementia care for all people with dementia, and thus rely upon the contributions of informal carers. For people with dementia, remaining in their own home is much more likely if the psychological wellbeing of caregivers is prioritised. Such a prioritisation is necessary, as significant prevalence of both depression (Gallagher-Thompson & Powers, 1997) and anxiety (Mahoney, Regan, Katona & Livingston, 2005) have been associated with dementia caregiving.

1.2.6 Role adjustment in dementia caregiving

The experiences of caregivers differ in terms of the burden they experience. Dementia caregiving has been associated with burden among caregivers, with the Zarit Burden Interview (ZBI) the most widely used measure (Hebert, Bravo & Preville, 2000). Whilst the concept of caregiver burden has been recognised for some time, researchers have recently started to document positive aspects of caregiving and caregiver resilience (Cherry, Salmon, Dickson, Powell, Sikdar, & Ablett, 2013). For example, a recent qualitative study found that dementia caregivers gain from the role, including an opportunity to give back, to discover personal strengths and increase relationship closeness (Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen et al., 2010).

1.2.7 Rationale

Until now, there have been no reviews of studies which have examined the role of religion/spirituality in the psychological wellbeing/role adjustment of BME informal dementia caregivers. Dementia is a global public health concern. Worldwide prevalence of dementia is growing (World Health Organisation, WHO, 2012) and is projected to double every 20 years, reaching 115.4 million in 2050. As the UK population ages, there will be an even more noticeable increase in dementia among the BME population due to the years in which people migrated to the UK. A previous systematic review was carried out in 2006 (Hebert et al., 2006) on the role of religion and spirituality in the wellbeing of caregivers. However, its focus was on all informal caregivers, without specific consideration of dementia caregivers, which is the focus for the present review. In addition, whilst it included studies with BME samples, this was not a specific aim of the Hebert et al. (2006) review. Regan, Bhattacharyya, Kevern & Rana (2013) carried out a systematic review, which did focus on religion among BME informal dementia caregivers, but which concentrated on dementia care pathways rather than psychological wellbeing/role adjustment among carers.

Finally, the diversity within ethnic groups is considerable, and should not be underestimated (Iliffe & Manthorpe, 2004). The focus upon religion and spirituality is therefore one measurable aspect of diversity which is tangible and can be measured across people from all BME groups.

1.2.8 Aim

The aim of the present review is to critically evaluate the empirical evidence regarding the role of religion / spirituality in the psychological wellbeing / role adjustment of BME

informal dementia caregivers. 'Role adjustment' can be considered to include both positive aspects of the caregiving role and caregiving burden. 'Psychological wellbeing' includes depression, anxiety, negative and positive emotion.

1.3 Method

1.3.1 Search strategy

A systematic literature search was conducted within PsychINFO, SCOPUS, Web of Science, Medline (Ovid) databases. The same search terms were used within all databases: (carer OR caregiv*) AND (multicult* OR diversity OR minority OR ethnic* OR Black OR Asian OR Latin* OR race) AND (Alzheimer* OR dementia) AND (spirit* OR relig*). The above terms were searched for 'anywhere' within Psychinfo, 'the title, abstract and keywords' within Scopus and Medline, and 'the title and topic' within the Web of Science. The search was not restricted to a particular time frame. The final search was completed in early May 2014, therefore studies published after this time could not be included due to the review deadline.

Study titles were screened initially to determine their relevance for inclusion in the present review. The abstracts of all relevant study titles were examined to determine whether they were primary research directly addressing the aim of the study and which met inclusion criteria for the study (see Table 1.1). Any remaining journal articles were then examined in their entirety in order to determine inclusion. A citation-based search was also conducted. Findings from the search were recorded on a 'Preferred Reporting Items for Systematic Reviews and Meta-analyses' (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) flow diagram (see Figure 1.1)

1.3.2 Selection criteria

Table 1.1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Peer reviewed journals English language journals Primary research Sample consists of current informal dementia caregivers Studies where findings for at least one ethnic minority group are reported. Studies including measures of both: 1. Religion or spirituality 2. Role adjustment or psychological wellbeing	Book chapters, editorials, reviews Studies including bereaved former-caregivers or professional caregivers Studies of caregivers when the illness of care-receiver is not dementia and/or dementia caregivers are analysed alongside other caregivers Studies examining solely physical health outcomes

1.3.3 Systematic search results

In total 155 articles were retrieved, of which 80 were duplicates, leaving a remaining 75 studies for consideration against the inclusion and exclusion criteria. A total of 15 studies met the inclusion criteria. All of these studies were conducted in the USA. The search found no studies taking place in the UK or any other country.

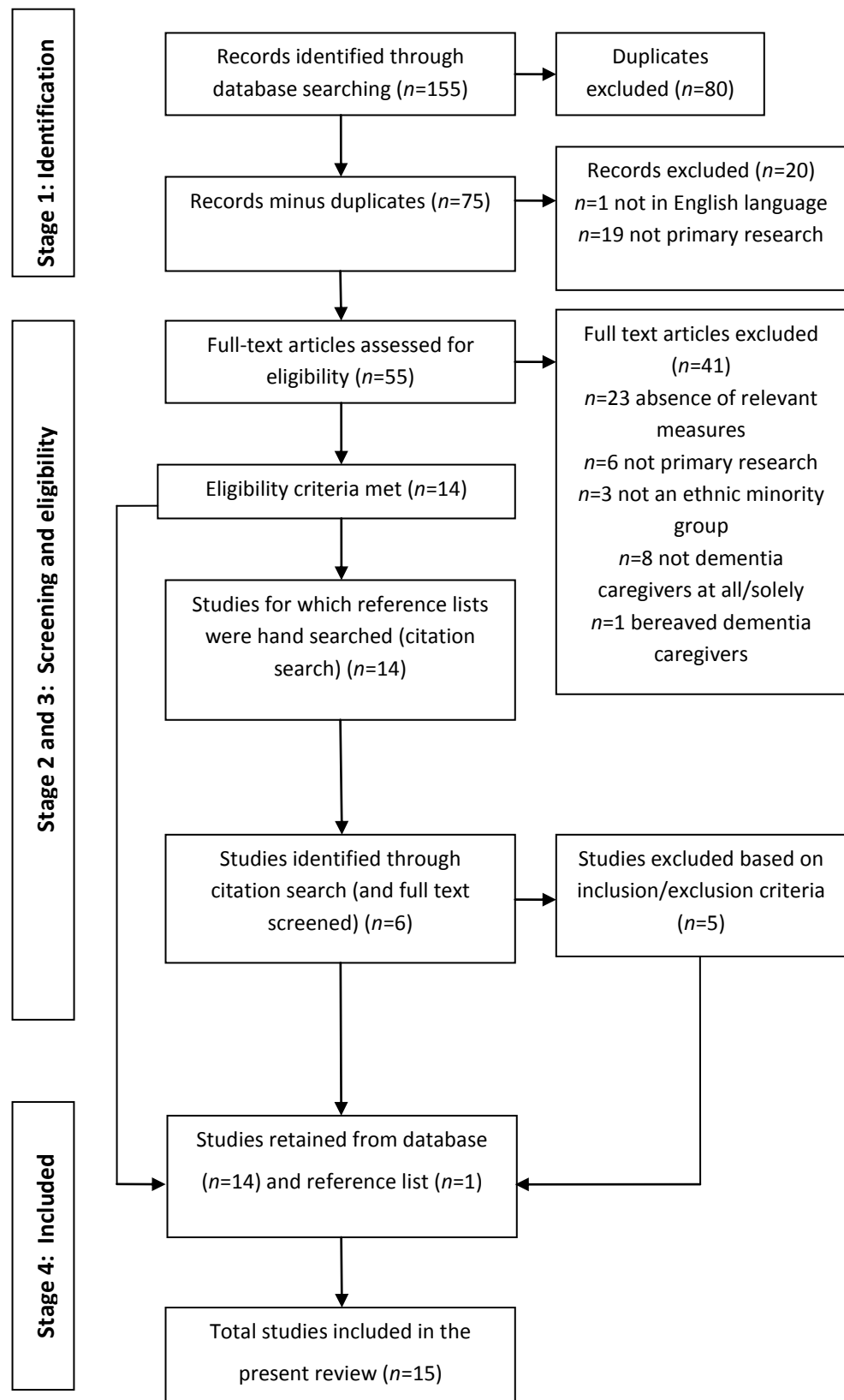


Figure 1.1: A PRISMA flow diagram of the study selection process (Moher et al., 2009)

1.3.4 Assessment of quality

The assessment of the quality of studies included in the present review was considered in relation to existing quality appraisal checklists (Glynn, 2006; Caldwell, Henshaw & Taylor, 2005; NICE, 2009; Downs & Black, 1998). The NICE guidance and Downs and Black (1998) quality frameworks were developed for intervention studies, therefore many items were not applicable to studies in the present review. Two quality appraisal tools (Glynn, 2006; Caldwell, Henshaw & Taylor, 2005) were developed for both quantitative and qualitative studies. However, Glynn's (2006) Evidence Based Library and Information Practice (EBLIP) critical appraisal checklist (see Appendix B) was selected for use in the present review as it provided the most relevant items for the present review's quantitative studies, as well as a clear scoring system. In addition, a previous study (Amini, Alavian, Kabir, Saiedi-Hosseini & Aalaie-Andabili, 2011) defined quality ratings (low<40%, moderate 40-70% and high >70%) for the EBLIP critical appraisal checklist, which have been adopted in the present review to rate studies (see Appendix C). Most of the studies were rated as moderate quality and only one study was rated of low quality (Morano & King, 2005). Therefore when considering the findings, this result should be acknowledged.

1.4 Results

The findings of the studies are summarised below in relation to the aim of the present review: to critically evaluate the empirical evidence regarding the role of religion/spirituality in the psychological wellbeing/role adjustment of BME informal dementia caregivers. The results are presented according to subject headings which are derived from the focus and findings of the reviewed studies.

1.4.1 Overview and critical analysis of studies

The study characteristics are summarised in Table 1.2, including the studies' design, sample, measures, statistical analysis and results which directly relate to the aim of the present review.

1.4.1.1 Aim

The studies included in the present review did not all have the same aim. However, all studies focused on informal dementia caregivers, with at least one BME group represented. Some studies explicitly set out to examine the differences between ethnic groups: on measures of religiosity/religious coping (Mausbach, Coon, Cardenas & Thompson, 2003), on psychological wellbeing over time (Skarupski, McCann, Bienias & Evans, 2009). Some studies had more than one aim, for example Mausbach et al. (2003) also explored predictors of positive religious coping and examined the relationship between acculturation and religiosity / religious coping in Latina caregivers.

1.4.1.2 Design

Of the total of 15 studies, 13 were cross-sectional, one was a randomised clinical trial, including baseline and follow up data, and one was longitudinal, obtaining outcome measures at 3 month intervals over 4 years (Skarupski et al., 2009). A cross-sectional study design can establish whether relationships between variables are significant. However, conclusions cannot be made about the direction or cause of the effect. The longitudinal study and randomised clinical trial therefore had advantages over the remaining studies.

1.4.1.3 Sample

The sample sizes were typically large across the studies. Those using data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) programme recruited large

sample sizes across multiple sites. There were six studies using REACH I data and four studies using REACH II data. However, not all studies include participants from the same REACH sites (see column 1 Table 1.2 for included sites).

Some of the REACH I studies used the same pool of participants in their analysis, with varying levels of overlap. For example, Thompson, Kinoshita, Coon, Mausbach and Gallagher-Thompson (2002) and Mausbach et al. (2003) have the same sample size and sample characteristics. However, there is no overlap in the measures used in the analysis, so the studies each make a distinct contribution to the literature. In other studies, the overlap is not so clear. For example, Roff, Burgio, Gitlin, Nichols, Chaplin and Hardin (2004) used data from three of the four sites included in the Haley et al. (2004) study, therefore there may be some overlap in the sample. Among REACH II studies, Hodge and Sun (2012) and Sun and Hodge (2014) used the same sample. Another two studies recruited from the same sites (Heo & Koeske, 2011; Lee, Czaja & Schulz, 2010). However, there may be little or no overlap in the samples, as the sample characteristics are not the same and the Lee et al. (2010) study required data collection at two time points.

Among non-REACH studies, Sun, Kosberg, Leeper, Kaufman and Burgio (2010) and Kosberg, Kaufman, Burgio, Leeper and Sun (2009) used the same sample, the former examining relationships between variables whilst the latter used only descriptive statistics. There were a remaining three studies which did not have any cross over in their samples with any other studies (Skarupski et al., 2009; Spurlock, 2005; Morano & King, 2005).

1.4.1.4 Inclusion/exclusion criteria

Studies using the REACH I programme participants had the same inclusion/exclusion criteria, specified both for the caregivers included in the study and the care-receivers. Caregivers had to be at least 21 years old, caring for a family member with dementia for at

least 6 months, for at least 4 hours a day. Some REACH I studies specifically indicate that the caregiver must be living with the care-receiver (Mausbach et al., 2003; Coon et al., 2004). However, others do not refer to this inclusion criteria specifically (Thompson et al., 2002), but direct the reader to other papers for further information.

In REACH I studies, care-receivers had to have a Mini Mental State Examination (MMSE) score of 23 or less, have a documented diagnosis of dementia, be unable to perform two or more Instrumental Activities of Daily Living or one or more Activities of Daily Living. Both caregivers and care-receivers were excluded if they were undergoing chemotherapy or radiation therapy for cancer or had undergone more than three hospitalisations in the last year. Caregivers were excluded if they were terminally ill; care-receivers were excluded if they were at risk for placement in a nursing home within the next 6 months.

1.4.1.5 Recruitment

The studies all used purposive or convenience sampling. Those which used data from REACH, a multi-site intervention for dementia caregivers, used the data collected at baseline before any intervention took place, excluding the randomised clinical trial (Lee et al., 2010). However, the fact that the studies were recruiting caregivers to participate in interventions may indicate that the participants were not typical of all informal dementia caregivers, such as those who would not seek caregiving support. For example, Lee et al. (2010) specified that caregivers must be reporting distress for inclusion in the intervention “(e.g. felt overwhelmed, angry, frustrated)” (p.187).

The REACH study sites used locality specific recruitment strategies designed to enhance the recruitment of BME populations, including building links with the Latino community and advertising through the media, as well as recruiting via health services (Hodge & Sun, 2012). This is an advantage of these studies.

Skarupski et al. (2009) acknowledge recruitment as one of their study limitations, as all participants were recruited via a dementia clinic, so were already using medical services, which will have skewed the sample, possibly leading to biased findings.

1.4.1.6 Age

The age of participants varied between the ethnic groups that were considered in the studies. In some studies, Latino American caregivers were significantly younger than White American caregivers (Mausbach et al., 2003; Coon et al., 2004), African American caregivers were significantly younger than White American Caregivers (Spurlock, 2005; Roff et al, 2004; Haley et al., 2004) and Cuban American caregivers were significantly older than 'Other Latino American' (including Mexican, Puerto Rican and other Latino Americans) caregivers (Sun & Hodge, 2014). However, not all studies showed this pattern, as in one study Latino American caregivers were slightly older ($p < .05$) than African American and White American caregivers (Heo & Koeske, 2011).

Age differences could have an impact on the results of the studies. While some studies did account for differences in age, by controlling for age in the statistical analysis, other studies did not do this.

1.4.1.7 Gender

As the majority of studies included a high proportion of female informal dementia caregivers (Mausbach et al., 2003; Thompson et al., 2002: included only females), it may be difficult to generalise the findings of the studies to male caregivers. However, studies were limited to those willing to participate and acknowledge this limitation.

1.4.1.8 Demographic features of the sample

Mausbach et al. (2003) and Thompson et al. (2002) reported that Latino Americans had a lower income, were less likely to be unemployed, and had fewer years of formal education. More acculturated Latino Americans had more years in education, more professional job roles and higher income than less acculturated Latino Americans. Heo and Koeske (2011) found fewer years in education and lower income among Latino Americans, followed by African Americans and then White Americans.

1.4.1.9 Study measures

The studies frequently reported Cronbach's alpha, demonstrating internal consistency of measures (Lee et al., 2010). However, none of the studies report other measures of reliability, such as test-retest reliability. Studies typically do not indicate the validity of measures. Exceptions to this are Sun and Hodge (2014), Hodge and Sun (2012) and Spurlock (2005). Other studies which used data from REACH refer to other articles for the full details of the study methodology, so may not include information about validity, assuming the reader will find the articles to which they refer.

1.4.1.9.1 Measures of religion

The measures of religion vary, and the distinction between religiosity and 'religious coping' is not clearly defined, as some studies use these terms interchangeably, whilst others consistently use just one of the terms; or distinguish between the two (Heo & Koeske, 2011).

Religiosity typically refers to frequency of attendance at religious services/activities ("attendance"), frequency of prayer/meditation ("prayer") and self-rated importance of religion ("importance"). Some group these together into one religiosity score (Coon et al.,

2004; Roff et al., 2004; Haley et al.; 2004), whilst others have included 'attendance' and 'prayer' as separate variables in the analysis (Heo and Koeske, 2011).

'Religious coping', on the other hand, specifically addresses how religion helps caregivers in their caregiving role (e.g. 'turning to God as a source of comfort'). Whilst some studies make this distinction between "religiosity" and "religious coping" (Heo & Koeske, 2011), other studies use measures which combine both domains ("religiosity/religious coping"; Skarupski, 2009; Sorensen & Pinquart, 2005).

In measures which combine religiosity/religious coping, participants are asked additional questions, for example, to rate whether attendance or prayer 'help with caregiving?' (Sorensen and Pinquart, 2005), or 'how much is religion or spirituality a source of strength and comfort to you?' (Skarupski et al., 2009).

A study which explored spiritual wellbeing in more detail included a 20-item measure, with two subscales: religious wellbeing and existential wellbeing (Spurlock, 2005). A copy of this measure is not available in that article. However, it appears to be more detailed than the other measures, which tend to be one to six items in length.

Another study (Thompson et al., 2002) which used a different measure, included a broader 'Older Persons Pleasant Events Schedule (OPPEs)', where participants were asked to rate items on frequency and perceived pleasure of the event (whether or not they had engaged in the activity). One subscale was 'spirituality' and examples of items are given ('feeling a divine presence' or 'going to church'), but the number of items is not indicated. The caregiving participants asked to complete it were not all in the older age range. However, it is unknown how this may have affected the scores.

The Brief Religious Coping Scale (short form), 'BRCOPE' was used to assess both positive religious coping ('Tried to find a lesson from God in this', 'Looked to God for strength,

support and guidance in this'), and negative religious coping ('Wondered whether God had abandoned us', 'Felt that my relative's dementia was God's way of punishing me for my sins and my lack of spirituality') on a 4 point-Likert scale (Mausbach et al., 2003). Heo and Koeske (2011) measure positive religious coping only, whereas Lee et al. (2010) refer to religious coping, and do not specify use of the BRCOPE nor the distinction between positive and negative religious coping.

Another research group (Kosberg et al., 2007; Sun et al., 2010) adopted a 60-item (15-subscale) COPE scale, which included 'turning to religion' as one four-item subscale. Religion was the most frequently used coping strategy among African Americans (Kosberg et al., 2007). The four-items are given in the Sun et al. (2010) paper as 'I put my trust in God', 'I seek God's help', 'I try to find comfort in my religion' and 'I pray more than usual' which are rated on a 4-point Likert scale.

1.4.1.9.2 Measures of positive aspects of caregiving

Haley et al. (2004) and Roff et al. (2004) both use the Positive Aspects of Caregiving (PAC) measure. However, Haley et al. (2004) uses an 11-item and Roff et al. (2004) a 9-item version.

1.4.1.9.3 Measures of Depression

The most frequently used measure for depression was the 'the Centre for Epidemiological Studies – Depression' (CES-D) scale. However, a report on the psychometric properties of the CES-D among a sample of ethnically diverse older adults, found that reverse scored (positively worded items) were less internally consistent and some responses negatively correlated with non-reversed items (Carlson et al., 2011).

The Mausbach et al. (2003) study used the Geriatric Depression Scale (GDS). However, the caregiving participants asked to complete it were not all in the older age range (Latino participants: mean age 51.76 years (SD 12.89), White participants: mean age 61.45 years (SD 13.03)). These results therefore need to be interpreted with caution.

1.4.1.9.4 Translation of measures

Measures were translated into Spanish for the Latino caregivers. Translation seemed to be carefully conducted and is outlined in detail by Thompson et al. (2002). Translated measures had good validity and reliability with Spanish speaking caregivers (Sun and Hodge, 2014).

Table 1.2 Summary of study characteristics

Author, publication year and location	Design	Sample			Measures		Statistical analysis		Results
		Sample size	Sample characteristics	Religion/ spirituality	Role adjustment	Wellbeing			
Coon, Solano, Mausbach, Kraemer, Arguelles, Haley, Thompson & Gallagher- Thompson (2004) REACH I	Cross- section	420	229 White Americans (WA), 191 Latina Americans (LA) All female.	3-items (Importance, attendance at religious activities, frequency of prayer or meditation)	Positive aspects of caregiving scale (PAC) 11- item	Center for Epidemiologic al Studies- Depression (CES-D) (20- item) Spielberger State Trait Anxiety Inventory (10-item)	Multiple Linear regression and multiple logistic regression. Sensitivity analyses	Levels of depression (CES-D), and CES-D wellbeing scale - no sig. differences by ethnicity or level of acculturation. LA –rated higher on PAC. LA – reported more frequent prayer, attendance at religious activity and importance of religion. WA – used more anti-depressant medication	
Haley et al. (2004) USA REACH I	Cross- section	720	425 White Americans (WA) 295 African Americans (AA)	3 items (as above)	PAC 11-item (as above)	CES-D 20 item Speilberger State Trait Anxiety Inventory	ANOVA, ANCOVA, logistic regression, polytomous logistic regression	CES-D wellbeing subscale – AA higher wellbeing (all sites) WA – higher anxiety (only at Philadelphia site) WA – higher use of anti-depressant, aanxiolytic or other psychotropic medication AA – highest PAC, and lowest behavioural bother AA – higher scores on all 3 religiosity items	
Heo and Koeske (2011) REACH II	Cross- section	642	211 African Americans (AA), 220 White Americans (WA), 211 Hispanic Americans (HA)	Brief RCOPE (3 item) Religious behaviour (attend & pray)	Zarit caregiver burden interview	Center for Epidemiologic al Studies- Depression (CES-D) (20- item)	Correlation Structural equation modelling (SEM)	Religious coping associated with lower burden appraisal and lower depression. Religious attendance also associated with lower burden appraisal and lower depression. Higher negative correlation with depression than with burden. Burden appraisal partially mediates relationship between religious coping and depression. Direct path from religious attendance to depression.	

						Multi-sample SEM	Path from religious coping to depression significant for AA and WA but not HA. Religious coping significant predictor for burden appraisal only for AA. WA – religious coping not significantly correlated to burden appraisal HA – n.sig. correlations between religious coping and burden and religious coping and depression.
Hodge & Sun (2012) USA, REACH II	Cross-section	209	All Latino Americans (mean age: 58yrs, 82.3% female), av length of residence in the US 32 years. 34.6% Cuban, 21.6% Mexican, 21.2% Puerto Rican, 22.6% other Latino backgrounds.	Spirituality measured with 3 indicators: Prayer/meditation (1-item), religious service Attendance (1-item) Spiritual coping (6-item)	Positive aspects caregiving Scale (9-item PAC Scale) Zarit Caregiver Burden Inventory	Structural equation modelling (SEM)	Spirituality had a direct effect on PAC, and spirituality partially mediated effect of subjective stress on PAC.
Kosberg, Kaufman, Burgio, Leeper & Sun (2007)	Cross-section	141	67 African Americans (AA) 74 White Americans	Duke Religious Index 15-subscale COPE (of which 4 items include turning to religion)	Consequences of care index (CCI) 20-item measuring subjective burden	Univariate t-tests and chi-square tests	Sig. diff on one subscale of DRI – AA attended more religious services than WA Almost sig. WA more likely to engage in private religious practice Coping – AA more likely to use religion and denial, WA more likely to use acceptance and humor WA – higher CCI scores (greater burden) overall, and for subscales Personal/Social restrictions and Physical/emotional health.
Lee, Czaja & Schultz (2010) REACH II	Randomised clinical trial	642	212 Latino Americans, 219 White Americans, 211 African Americans	Brief Religious Coping (6-item; 4-point scale)	Zarit Caregiver Burden Interview (12 items)	Center for Epidemiological Studies-Depression (CES-D) (10-item) Hierarchical regression analyses	Sig diffs in religious coping between all 3 groups, AA more than LA, both more than WA. No sig. differences in depression. WA sig. more caregiver burden than AA, no sig diffs between LA and WA, nor LA and AA caregiver burden. For AA only, effect of intervention on depression was moderated by religious coping: AA with less religious coping in the intervention condition reported sig. greater decrease in depression, compared to AA with less religious coping in the information condition.

Mausbach, Coon, Cardenas & Thompson (2003) USA REACH I	Cross-section	257	147 White Americans (WA), (42.2% Protestant, 18.4% Catholic, 27.9% Other, 11.5% None), 110 Latina Americans (LA), (68.2% Catholic, 31.8% Protestant) (69% Mexican, 31% a mixture of Cuban, Puerto Rican Americans and Other) Inclusion criteria: female and aged 21 or over.	Global religious measures (3 items: organizational, non-organizational and subjective religiosity) BRCOPE: Brief Religious Coping Scale Positive and negative items		Geriatric depression scale (GDS)	Multiple regression analysis	Mental health (GDS) not a significant predictor of positive religious coping. Ethnicity remained a significant predictor of positive religious coping even when accounting for other independent variables (e.g. MMSE score) There was no significant interaction, therefore the contribution of independent variables in predicting positive religious coping did not differ for WA and LA.
Morano & King (2005) USA	Cross-section	343	25% African Americans; 32% Hispanic Americans; 42% White Americans	5 items scale; religion (2 items); spirituality (2 items), religion as a coping resource (1 item)	Self-acceptance (what degree caregiving impacted on way saw themselves)	CES-D center for epidemiologic studies depression scale	ANOVA Regression Analysis	WA highest depression and lowest self-acceptance No sig. difference in depression or self-acceptance between HA and AA AA highest level of religiosity, followed by HA and then WA. Increased religiosity associated with decreased depression. Religiosity associated with increased self-acceptance Religiosity partially mediated impact of problematic behaviours on self-acceptance. Religiosity did not mediate the effects of problematic behaviours on depression.
Roff, Burgio, Gitlin, Nichols, Chaplin & Hardin, 2004 USA REACH I	Cross-section	618	275 African American (mean age: 58.01, Spousal 26.91%) 343 White American (mean age: 65.62, Spousal 60.93%)	Religiosity 3 items (importance of faith or spirituality, attendance at religious services or activities and frequency of prayer or meditation)	Positive aspects of caregiving (9 item PAC scale)	Center for Epidemiologic al Studies-Depression (CES-D) (20-item) Spielberger State-Trait Personal Inventory (10-item)	Correlation Multiple regression	Sig. correlation between religiosity and PAC ($r=-.24$, $p<.05$), and between religiosity and anxiety ($r=-.13$, $p<.05$) Sig. correlation between race and PAC ($r=-.22$, $p<.05$) The relationship between race and PAC is partially explained by African Americans lower SES, lower behavioural bother, lower anxiety and higher religiosity.

Skarupski et al. (2009) USA	Longitudinal	307	African Americans (AA) n=74, White Americans (WA) n=229 (4 missing race values) 79 of 307 care-receivers were placed in a nursing home during the study. Participation rates over 4 years Median 80.8% (Range 76.1%-90.8%)	Religiosity (6 questions – 5 pt likert) Religiosity as a social resource	10 item measure of caregiver burden 5 item measure of caregiver satisfaction	CES-D center for epidemiologic studies depression scale Positive affect scale (5 item; 4-pt)	Correlation Generalised linear regression	Sig. negative correlation between religiosity and burden. Non-sig. correlation between religiosity and depression. No race differences in the intercept (baseline) for depression nor burden. Depression more likely to decrease over time among AA than WA. Burden scores tended to decrease for AA and increase for WA over time. Race differences were not accounted for by social factors including social support, religiosity and quality of past relationship.
Sorensen & Pinquart (2005) USA REACH I	Cross-section	1149	278 African American (mean year of birth: 1934, Female 82%, Spousal 26.3%) 653 White American (mean year of birth: 1933, Female 79.8%, Spousal 60.2%) 218 Hispanic (mean year of birth: 1939, Female 87.6% (mean age: 65.62, Spousal 40.8%))	Religious coping (5 item), Incl. freq. of attending relig. Services, praying, importance of religion, whether praying and participation in religious services help with caregiving.	Positive aspects of caregiving (11 item scale)	Center for Epidemiologic Studies-Depression (CES-D)	ANOVA Structural equation modelling	Religious coping most pronounced in AA and least in WA, with LA in between (all sig. diffs). PAC most reported in AA and least in WA. AA lowest depression scores and HA highest. AA received more informal support. More similarities than differences between ethnic groups in predictors of caregiver depression, for all 3 groups, receipt of information support, positive aspects of caregiving and religious coping all related to lower depression
Spurlock et al. (2005) USA	Cross-section	148	77 Caucasian (63% female, 29% spouse, 71 African American (61% female, 7% spouse) Total sample characteristics (Protestant 57.1%, Mean age: 58.93 (Range 26-91)	5-item Religious behaviours Spiritual Wellbeing Scale (SWBS), 10-item subscales x2: Religious Wellbeing Scale (RWB) and Existential Well-Being (EWB Scale)	Burden Interview Scale (BIS)		Correlation	Sig. negative relationship between spiritual wellbeing and caregiver burden ($r=-.493$, $p<.01$)

Sun & Hodge (2014) REACH II	Cross-section	209	All Latino Americans (As Hodge & Sun, 2012)	1 item (church attendance), 1 item (prayer /meditation) S/R coping (2 subscales: positive religious coping, negative religious coping)	Zarit Caregiver Burden Inventory 12-item	CES-D 10 item	ANOVA Hierarchical regression analysis	Cuban Americans sig. more depression, prayed less often than Mexican, Puerto Rican and Other Latino Americans. Cuban Americans sig. less church attendance and less S/R coping than Other Latino Americans (no sig. diff with Mexican or Puerto Rican Americans). Church attendance had a direct effect on depression (inverse relationship) and moderated the relationship between caregiver burden and depression. When caregiver burden was higher, church attendance had a greater effect on reducing depression.
Sun, Kosberg, Leeper, Kaufman & Burgio (2010) USA	Cross-section	141	74 White Americans (mean age: 53.5, 77% female, 10.8% spousal rel.) 67 African American (mean age: 49.4, 67.2% female, 9% spousal rel.)	Religious coping (4 item), Duke Religious Index (DRI; 5 item) incl. religious attendance (1), private religious activities (1), intrinsic religiosity (3)	CCI (consequences of care index)		Bivariate correlation Path analysis	3 indicators of religiosity inversely correlated to burden (organisational, intrinsic and religious coping) Non-sig. direct effect of race on caregiver burden. Organizational religiosity is the only sig. mediator between race and caregiver burden. However, only a small portion of the variance in caregiver burden is explained in the mediation model.
Thompson, Solano, Kinoshita, Coon, Mausbach & Gallagher-Thompson (2002) USA REACH I	Cross-section	257	147 White American 110 Latina Americans (69% Mexican, 31% a mixture of Cuban, Puerto Rican Americans and Other) All female	Older Persons Pleasant Events Scale (Spirituality subscale) 2 items: 'feeling a divine presence', 'going to church', 2 scores for each item: 'frequency' and 'pleasure', both rated using 3-point likert scales		CES-D	Correlation	WA – Spirituality the only scale not sig. related to depression LA – significant negative correlation between spirituality and depression

1.5 Key findings from the studies

1.5.1 Religion/spirituality among BME informal dementia caregivers

A general finding of the studies was that African American, followed by Latino American dementia caregivers, used religion and spirituality more frequently either generally (“religiosity”), as a coping strategy in their caregiving role (“religious coping”), or when both behaviours are reported in a combined measure (“religiosity/religious coping”), in comparison to White American dementia caregivers.

1.5.1.1 Religiosity and psychological wellbeing

Whilst several studies found religiosity to be higher among BME dementia caregivers (African Americans: Roff et al., 2004 & Haley et al., 2004; Latino Americans: Coon et al., 2004 & Mausbach et al., 2003), none of these studies found significant differences in reported depression. Among African Americans, Haley et al. (2004) found significantly higher scores on the wellbeing subscale (reverse scored items) of CES-D. However, as reverse scored items were found not to be psychometrically sound (see section 1.4.1.9.3) it is difficult to draw firm conclusions from this finding. Two studies (Haley et al., 2004; Roff et al., 2004) found significantly lower anxiety among African Americans, in comparison with White Americans. However, Coon et al. (2004) did not find any significant differences between Latino Americans and White Americans for wellbeing or anxiety. It is important to note that these studies report differences between groups on each measure separately, and did not perform correlation or regression analysis between religiosity and measures of psychological wellbeing. The exception to this is Roff et al. (2004) who found a significant

negative correlation between anxiety and religiosity (the relationship between depression and religiosity was not analysed).

There were noteworthy findings in studies which analyse the relationship between religiosity and psychological wellbeing. Heo and Koeske (2011) found that one measure of religiosity (attendance) was significantly negatively correlated with depression and reported a direct path in a structural equation model (SEM) between religious attendance and depression among African Americans. In contrast, whilst frequency of prayer/meditation had a significant negative correlation with depression, it did not significantly predict depression. Church attendance was also found to have a direct (negative) effect on depression using multiple regression analysis among Latino Americans (Sun & Hodge, 2014). However, prayer had no direct or indirect effects on depression after controlling for other variables (Sun & Hodge, 2014).

In a study measuring both frequency of and pleasure from spiritual activities, Latino Americans scored higher than White Americans (Thompson et al., 2002). The study found that pleasure from spiritual activities was significantly negatively correlated with depression for Latino Americans only.

1.5.1.2 Religiosity/religious coping and psychological wellbeing

In the two studies where religiosity/religious coping was combined into a single measure (Morano & King, 2005; Sorensen & Pinquart, 2005), there were significant differences between BME caregivers and White American caregivers for both religiosity/religious coping and depression. Religiosity/religious coping was highest among African Americans,

followed by Latino Americans and then White Americans (Morano & King, 2005; Sorensen & Pinquart, 2005). Morano and King (2005) found that White Americans had the highest depression with no significant difference between African Americans and Latino Americans. However, Sorensen and Pinquart (2005) report that Latino Americans had the highest depression, followed by White Americans and then African Americans the lowest depression. Religiosity/religious coping was negatively correlated with depression in the total sample (Morano and King, 2005) and within each ethnic group in separate analyses (Sorensen & Pinquart, 2005).

Skarupski et al. (2009) found that African Americans reported higher religiosity/religious coping than White Americans. However, they found no significant differences in self-reported positive affect.

1.5.1.3 Religious coping and psychological wellbeing

Among BME caregivers, religious coping (Lee et al., 2010) and positive religious coping (Heo & Koeske, 2011; Mausbach et al., 2003) were self-rated significantly higher in comparison with White caregivers, with no significant differences in negative religious coping (Latino Americans: Mausbach et al., 2003) or depression (Lee et al., 2010; Heo & Koeske, 2011). Heo & Koeske (2011) found that African Americans had the highest positive religious coping, followed by Latino Americans and then White Americans. They found a significant negative correlation between positive religious coping and depression. However, in two studies using regression analysis, religious coping was not a significant (negative) predictor of depression among Latino caregivers (Mausbach et al, 2003; Sun & Hodge, 2014).

The only randomised clinical trial included in the present review, found that for African Americans only, the effect of the intervention on depression was moderated by self-reported religious coping (Lee et al., 2010). Among African Americans with less religious coping, those in the “intervention condition” reported significantly greater decrease in depression, compared to those in the “information condition”. The same finding was not present for African Americans with more religious coping, suggesting that the intervention may not be sufficiently beneficial for those caregivers.

1.5.2 Religion / Spirituality and role adjustment

1.5.2.1 Caregiver burden

BME caregivers reported significantly lower caregiver burden, alongside higher religiosity (Latino Americans: Coon et al., 2004; African Americans: Roff et al., 2004; Haley et al., 2004) and higher spiritual wellbeing (African Americans: Spurlock, 2005), in comparison with White Americans.

There is further evidence (Kosberg et al., 2007) to indicate African Americans’ significantly lower caregiver burden, alongside higher religious coping and higher attendance at religious activities. In contrast to other studies, Kosberg et al. (2007) found White Americans were slightly more likely to engage in private religious practices than African Americans. However, this finding was just non-significant ($p=.06$) and therefore cannot be given much weight.

Heo and Koeske (2011) found that African Americans reported the least burden, followed by Latino Americans and then White Americans (who reported greatest burden). Religious coping, attendance and prayer were all significantly negatively correlated with caregiver burden (Heo & Koeske, 2011). Spiritual wellbeing was also negatively correlated with caregiver burden (Spurlock, 2005), within the total sample.

The only longitudinal study (Skarupski et al., 2009) found differences in the reports of caregiving burden over time, decreasing for African Americans whilst increasing for White Americans (a significant finding only for participants living in the same household as the person with dementia). This finding was not accounted for by levels of self-reported religiosity/religious coping.

1.5.2.2 Positive aspects of caregiving

Studies which included measures of both positive aspects of caregiving (PAC) and religiosity or religiosity/religious coping, consistently found higher scores on both measures among BME dementia caregivers. African Americans (Haley et al., 2004; Roff et al., 2004; Sorensen & Pinquart, 2005) and Latino Americans (Coon et al., 2004; Sorensen & Pinquart, 2005) self-rated significantly higher for PAC than White Americans. In addition, Roff et al. (2004) found a significant positive correlation between PAC and religiosity.

Hodge and Sun (2012) found that the reported frequency of Cuban Americans' attendance and prayer was lower than 'Other Latino Americans' (including Mexican, Puerto Rican and other Latino Americans), but there were no significant differences in religious coping.

When combined into an overall religiosity/religious coping score, this significantly correlated with PAC within the total sample.

1.5.2.3 Other aspects of role adjustment

In contrast to the findings on lower caregiver burden and increased PAC among African Americans (see sections 1.5.2.1 and 1.5.2.2), Skarupski et al. (2009) found no significant differences between African Americans and White Americans in reports of satisfaction from caregiving. However, the same study did support findings from other studies to show that African Americans reported higher religiosity/religious coping. This study was rated 'High' in the assessment of quality.

Additionally, a measure of self-acceptance, used in one study (Morano & King, 2005) can be considered to be among "other aspects of role adjustment". Morano and King (2005) showed increased self-acceptance alongside increased religiosity/religious coping. It is important to note that African Americans scored highest on both of these measures in this study. It is important to note that this study was rated as 'Low' in terms of quality.

1.5.3 Are there any factors which mediate the relationships described above?

Using path analysis to examine data in their study, Heo and Koeske (2011) found a statistically significant indirect path between religious coping and depression via burden appraisal, suggesting that religious coping influences caregivers' appraisal of the caregiving situation, which has an impact on depression. However, this was only significant for African Americans.

Sun et al. (2010) also used path analysis and found that organizational religion (attendance) was a significant mediator of the relationship between ethnicity and burden. However, this only partially explained the variance in caregiver burden. In addition, a multiple regression analysis (Roff et al., 2004) found that the relationship between ethnicity and PAC was partially explained by several factors including religiosity.

However, when another factor (problematic behaviour) was included in the analysis (Morano & King, 2005), no support was found for the authors' hypothesis that religiosity/religious coping would mediate its effect on depression and self-acceptance. However, due to the low quality rating of this study, this finding should be considered with caution.

1.5.4 Other explanatory factors

Studies did account for differences between ethnic groups, for example in income and education, type and quality of relationship with the care-receiver. Sorensen and Pinquart (2009) identified more risk factors for depression, other than 'less religious coping'. These included being female, being a spouse, greater memory and behavioural problems in the person with dementia, less informal support and less use of PAC.

1.5.4.1 Relationship to the care-receiver

The relationship to the care-receiver was measured in terms of the type of relationship: spouse, adult child or other family member. All studies included family caregivers only. BME caregivers were more likely to be an adult child or other family member. The

relationship quality prior to the onset of dementia has also been recorded. Skarupski et al. (2009) did not find support for quality of relationship accounting for decrease in African Americans' caregiving burden over time.

1.5.4.2 Characteristics of the care-receiver

Sorensen and Pinquart (2005) found that the most significant predictors of caregiver depression are the care recipients' memory and behaviour problems. They did not find support for the hypothesis these effects would be less among African Americans. Greater problematic behaviour was also found to result in higher depression and lower self-acceptance (Morano & King, 2005). Religiosity was associated with decreased depression and increased self-acceptance. The association between religiosity and self-acceptance was partially mediated by the impact of problematic behaviours. However, the association between religiosity and depression was not partially mediated by the impact of problematic behaviours.

1.5.4.3 Social support

Several of the reviewed studies include a measure of social support (Roff et al, 2004; Skarupski et al., 2009; Sorensen & Pinquart, 2005). However, not all of them included one (Mausbach et al., 2003; Thompson et al., 2002; Spurlock, 2005, Haley et al., 2004; Coon et al., Heo & Koeske, 2011; Sun et al., 2010; Kosberg et al., 2007; Morano & King, 2005) Social support has been proposed as an explanation for the positive effects of religiosity on caregiving (Skarupski et al., 2009). Sorensen and Pinquart (2005) found that both informal support and religious coping were related to lower depression, among all ethnic groups.

However, the study measured these individually. In a model for explaining positive aspects of caregiving (PAC) among Latino caregivers, Hodge and Sun (2012) found that religion retained a significant contribution, despite the inclusion of social support. Therefore based on these findings, religion retains a positive contribution over and above social support. In contrast to this, Skarupski et al. (2009) found neither religiosity/religious coping nor social support to account for the decrease in African Americans' caregiver burden over time.

Roff et al. (2004) expected African Americans to have more social support in comparison with White Americans but this was not found to be the case despite increased religiosity. Their finding that positive aspects of caregiving are higher among African Americans could not be explained by social support. In addition, among Latino Americans, the relationship between church attendance and depression remained significant even after adjusting for social support (Sun & Hodge, 2014).

1.5.4.4 Caregiver physical health

Poorer self-rated physical health was strongly related to higher burden and depression but unrelated to attendance, prayer and religious coping (Heo & Koeske, 2011). Sorensen and Pinquart (2005) found that religious coping, informal support and PAC were unrelated to caregivers' perceived physical health. In contrast, another study found that poorer physical health was related to more positive religious coping (Mausach et al., 2003).

1.5.4.5 Acculturation

Higher acculturation scores were associated with less positive religious coping (Mausbach et al., 2003). Mausbach et al. (2003) used the revised version of the Acculturation Rating Scale for Mexican Americans (ARSMA-II), Anglo Orientation Subscale (AOS) and the Mexican Orientation Subscale (MOS; rephrased for Latina caregivers of other origins, e.g. Cuban), average scores on the AOS were subtracted from average scores on the MOS to obtain an acculturation score.

In contrast, two studies (Sun & Hodge, 2014; Hodge & Sun, 2012) used only years living in the USA as an indicator of acculturation, which is acknowledged in these studies to be limited in its scope. Despite this, it is important to note that 'years living in the US' was unrelated to depression, caregiving burden, attendance, prayer and religious coping.

1.5.4.6 Subgroup analyses

In studies which compared ethnic groups, significant differences were found between groups in age, education, employment and gender. However, not all studies completed subgroup analyses matched for these factors. This was explained by one study as being due to small sample size (Spurlock, 2005). However, other studies had a large enough sample size. For example, Coon et al. (2004) completed subgroup analyses matched for education, employment or kinship status, and found that key findings from the study remained the same. Mausbach et al. (2003) found that ethnicity remained a significant predictor of positive religious coping even when accounting for other variables.

Haley et al. (2004) controlled for SES, gender, age and severity of memory and behaviour problems. The finding that African Americans were less depressed was no longer significant, whilst other study findings remained significant.

Sun et al. (2010) excluded those variables from their mediation model which neither significantly relate to ethnicity nor caregiver burden. For example, whilst age differed by ethnicity, age was not related to caregiver burden, so could not be used to explain the differences in caregiver burden.

1.6 Discussion

The aim of the present literature review was to critically evaluate the empirical evidence regarding the role of religion/spirituality in the psychological wellbeing / role adjustment of BME informal dementia caregivers. The findings in the present study all relate to BME dementia caregivers living with or at least sharing kitchen facilities with the care-receiver (Lee et al., 2010). They are all also family members. Therefore the results are limited to this group of dementia caregivers.

1.6.1 Summary of findings

The present literature review found that African Americans and Latino Americans report higher religiosity, use religion more as a coping strategy, are less burdened by their caregiving role and report a higher number of positive aspects of caregiving, in comparison with White Americans. The prediction of some studies that African Americans would be less depressed, based upon their higher religiosity and religious coping, was not supported, especially when considering the poor psychometric properties of reverse scored items on the CES-D (Carlson et al., 2011). The findings for Latino Americans were also mixed, with higher reported depression in one study (Sorensen & Pinquart, 2005).

Religiosity and religious coping were nevertheless found to be negatively correlated with depression. However, religiosity and religious coping were not significant negative predictors of depression in regression analyses. Therefore, whilst a correlation between the two factors exists, a causal relationship (religion reduces depression) cannot be concluded. Despite this, religious attendance, when analysed alone, led to decreased depression in a

path analysis (Heo & Koeske, 2011). Religious attendance also partially explained the relationship between ethnicity and caregiver burden among Latino caregivers (Sun & Hodge, 2014). Religiosity retained its contribution to increased PAC, alongside other factors (Roff et al., 2004). Therefore benefits of religiosity and religious coping have been shown to exist.

In the only longitudinal study (Skarupski et al., 2009), African American dementia caregivers' depression reduced over time, but was not accounted for by religiosity, social support or quality of past relationship, suggesting that other factors are also important and require further investigation. In the only randomised clinical trial (Lee et al., 2010), the needs of BME dementia caregivers with high religious coping are not being met through interventions in the REACH programme, as their depression did not reduce.

1.6.2 Research implications

Clearer definitions of religiosity, religious coping and spirituality are required in future studies. Only one study described 'spiritual wellbeing' as a measure. However, it was unclear in this study how religion is distinguished from spirituality. Studies need to include their measures as much as possible so that research can be replicated. Separate analyses of different religiosity domains, such as 'religious attendance', are likely to be important to understand their contribution further.

A criticism of the field of 'ethnicity' in general, is that it puts groups together and neglects to reflect and consider the considerable diversity within a defined ethnic group (Iliffe & Manthorpe, 2004). This criticism applies to the groupings used in the present studies,

including 'Latino American' and 'African American'. Acculturation is one way of representing diversity within a defined ethnic group, and was considered by three of the studies in the present review (Sun & Hodge, 2014; Hodge & Sun, 2012; Mausbach et al., 2003).

It may be more important to use different characteristics rather than solely ethnicity to understand the diverse experiences and needs of dementia caregivers. For example, at a local level, communities with shared culture and beliefs, including people from diverse ethnic origins could be researched as a group. This might include those living in a particular area, or those who attend a particular Church, Mosque or Temple.

In addition, there were no studies exploring the needs of recent migrants to the UK. Their needs and experiences are likely to be different from those of British or American citizens, although their ethnic origins may be similar. The acculturation measure from the Mausbach et al. (2003) study goes some way to address this.

The search revealed no UK studies which have studied the influence of religion/spirituality on role adjustment/wellbeing of BME informal dementia caregivers. Regan (2014) found that many UK studies group religious variables with 'cultural' ones. Therefore 'religion' is not measured as distinct from 'culture'. This may explain the paucity of UK studies measuring religion/spirituality among BME dementia caregivers. One study (Parveen, Morrison & Robinson, 2013), which did include religious coping, grouped dementia caregivers alongside other caregivers, and therefore did not meet criteria for inclusion in the present review. However, they found that British South Asian caregivers used more

religious coping than White British caregivers. Studies which include BME dementia caregivers have measured 'familism' (a strong identification and attachment to family members) both in the UK (Parveen et al, 2013) and USA (Sayegh & Knight, 2010). Therefore a future review may benefit from including 'familism' as well as religion/spirituality.

Lee et al. (2010) measured depression as an indicator of the relative success of their caregiver interventions. However, reduction in depression is not the only way of determining benefits from interventions. It may be useful to evaluate interventions further through feedback from caregivers via questionnaires or qualitative research. Future intervention studies and longitudinal studies are recommended in order to better establish changes in psychological wellbeing/role adjustment over time.

Although it was not a focus of the present review, both Latino Americans and African Americans had poorer self-reported physical health. Therefore BME dementia caregivers in the US, suffer both psychological and physical consequences of caregiving, despite being less burdened and reporting more positive aspects of caregiving. This supports the rationale for further research among BME dementia caregivers in order to better support them in their roles. In addition, psychological distress may be somatised, therefore future research or reviews may find it helpful to consider physical health alongside psychological wellbeing.

1.6.3 Clinical implications

The review findings suggest caregivers' religion plays an important part in reducing caregiver burden and increasing PAC. This suggests that it may be important for health care

professionals to receive training in talking about religion and spirituality with dementia caregivers, and to tailor interventions to support continued use of religious coping when this is valued by caregivers. Interventions which fail to explore religiosity and religious coping may at worst alienate caregivers or at least miss opportunities for better supporting them. Teaching in spiritual care has been found to improve clinical practice among nurses (Cone & Giske, 2012).

Other reviews have shown that BME dementia caregivers are less likely to access formal health services (Mukadem, Cooper & Livingston, 2011), where their religious needs may not be met (Regan et al., 2013). Health services may need to support existing networks, and focus on enabling religious practice and access to places of worship. This could take place through greater communication, liaison and joint working with religious representatives, community organisations and diverse faith communities. This could include sharing information, best practice and advice.

1.6.4 Limitations of the review

The scope of the present review is limited, with all studies coming from the USA and only a narrow segment of BME populations represented. Therefore, whilst being of relevance to BME caregivers in the USA, it may have less applicability in informing UK support and services for BME dementia caregivers. The experiences and needs of BME dementia caregivers in the UK are likely to be different from those in the USA. In particular, studies which focus on Latino American caregivers' may be less relevant to BME populations in the UK, when UK BME dementia caregivers are more likely to be first, second or third

generation caregivers from the Republic of Ireland, India, Pakistan and Jamaica (Office for National Statistics, 2011).

A second limitation of the present review is the type of research included, with a range of differing measures across studies, and a majority of cross-sectional study designs. The measures may be tapping into different constructs, for example there are likely to be differences between religion, spirituality and religious coping, which were not always accounted for in the studies. In addition, as they included different measures of psychological wellbeing / role adjustment, this meant that there were a limited number of studies which included measures of caregiver burden (eight) or PAC (five). Whereas eleven studies included measures of depression, therefore it is easier to make conclusions about the non-significant depression results. Future research should aim to use measures more consistently, to facilitate comparison of findings between different studies. In addition, there was only one longitudinal and one intervention study included in the present review. The literature in this area would benefit from more of these studies and should therefore be a consideration for future research design.

A third limitation of the present review is the inclusion criteria requiring studies to have specific measures of psychological wellbeing/role adjustment and religion/spirituality. Although this was an important inclusion criterion in order to draw conclusions across studies about specific constructs (such as religiosity and caregiver burden) and to compare measures, it nevertheless excluded all qualitative research in the area. A future systematic review focusing on qualitative research in this area will be important to complement and expand on some of the findings from the present review.

1.6.5 Conclusions

Religion and spirituality are important factors, which are associated with reduced caregiver burden and increased PAC among BME dementia caregivers in the US. The importance of religion and spirituality should be considered alongside other factors and not ignored. It will be important to identify those dementia caregivers who use religious coping in their caregiving role and support them to maintain these existing resources. Religious attendance may provide an additional beneficial contribution, over and above social support and religious beliefs in general. Investigating the mechanisms underlying this relationship is a potential further avenue for future research. The present review brings together the existing research in this area and highlights some methodological considerations which could be improved in future studies.

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Chapter Two: Empirical Paper

Trainee clinical psychologists' experiences of working with older people: An Interpretative Phenomenological Analysis

In preparation for submission to *Clinical Psychology and Psychotherapy* (see Appendix D for Author Instructions)

Overall chapter word count (excluding tables, figures, footnotes and references): 7,542

2.1 Abstract

Trainee clinical psychologists are required to work with people across the lifespan during their training. Their experiences of working with older people have not previously been explored using qualitative methods. Interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009) was used to conduct qualitative analysis of data from semi-structured interviews with participants, in order to gain rich detail about their individual lived experiences. The three superordinate themes to emerge from the transcript data include: 'hearing people's stories', 'reminders of mortality' and 'overcoming challenges to the professional role'. The findings have implications for clinical psychology training courses in preparing trainees for working with older clients. The findings are considered in terms of the clinical implications and future research.

2.2 Introduction

Trainee clinical psychologists are those currently completing a Health and Care Professions Council (HCPC) approved and British Psychological Society (BPS) accredited Doctorate in Clinical Psychology. This is the principle training route to be able, upon completion, to register and work as a Clinical Psychologist in the United Kingdom (UK; HCPC, 2012). Applicants to UK Clinical Psychology training courses must have completed a graduate level qualification in Psychology with Graduate Basis for Chartered Membership, a standard set by the BPS (Clearing House, 2013).

Trainee clinical psychologists are increasingly likely to be involved in the provision of services to older people post-training, as the older population grows. In 2013, the Office for National Statistics (ONS) estimated that there were 10.8 million people aged 65 and over living in the UK, 17% of the UK population (ONS, 2013) and projections suggest this proportion will grow to 23% by 2033 (ONS, 2009). Those born in the baby boom after World War II are currently either in or approaching their 60s and those born in the baby boom of the 1960s will reach 65 from 2025 onwards (ONS, 2012). 'The Faculty of Psychology of Older People' (FPOP), previously known as 'Psychologists' Special Interest Group for the Elderly' (PSIGE), was established in 1980 (PSIGE, 2013) and has been instrumental in embedding the psychology of older people within clinical psychology training courses in the UK (Straughan, Kneebone, Vetere & Vandrevalla, 2010). The importance of core placements with older people as part of training was increasingly recognised in the 1990s (Woods, 2008). However, it is no longer a requirement, providing that courses meet BPS standards for training where, *'A fundamental principle is that*

trainees must work with people across the lifespan' (p.22; BPS, 2012). Trainees can gain experience of working with older people in older people's mental health services, as well as in other specialities, including physical health and neuropsychology.

There has been limited research into the unique aspects of working with older people among pre-qualified clinical psychologists. A recent article in the FPOP newsletter (Hewett, 2014) proposed a conceptual model for the development of attitudes towards working with older people using findings from a mixed methods study. Personal and professional experiences influenced participants' attitudes, skills development and subsequent decision to work with older people. A recent unpublished doctoral study (Heinson, 2012) suggested that clinical psychologists' childhood attachment may influence the decision to work with older people, but the experiences were diverse and a more important factor was work experience with older people early in career. A recent article in the Division of Clinical Psychology (DCP) publication 'Clinical Psychology Forum', presented the views and experiences of the pre-qualification group column authors on ageing, psychological therapy and barriers to care (Persson & Teale, 2013). They highlight and challenge stereotypical views, including resistance to therapy and therapy ineffectiveness with older people.

In addition to the most recent interest described above, two published studies have examined trainees' views and attitudes about working with older people. Firstly, Lee, Volans and Gregory (2003a) surveyed trainee views on recruitment to work with older people and secondly, Lee, Volans and Gregory (2003b) surveyed trainee attitudes towards psychological therapy with older people. Both studies recruited the same population of trainee clinical psychologists across 25 UK clinical psychology training programmes

(response rate 41%; Lee et al., 2003a) from all three cohorts (1996-1998 intakes to the courses). 'Reasons for poor recruitment' to work with older people, given by respondents included 'fewer positive outcomes' (45%), 'personal issues' (43%), 'low profile' (36%), 'ageism' (22%) and 'training/experience issues' (16%) as well as ten other categories (3-12%). However, as the authors acknowledge, the question phrasing failed to make clear whether responses represented personally held views or presumptions about others' views. The most frequently reported suggestions for improving recruitment to the older adult specialty were 'good quality placements and/or teaching on training courses' (45%), and 'improved marketing of the role of older adult psychologists' (39%), followed by 'improved terms and conditions and more support' (14%).

Lee et al., (2003b) report attitudes towards psychological therapy with older people among clinical psychology trainees, also collected via postal survey. A fixed choice (yes/no) questionnaire on barriers to psychotherapeutic work with older people, yielded the highest agreement (74.4%) for 'difficulties with memory'. On a 7-point Likert scale, 60% of participants responded '7' (a great deal) when asked 'whether working with older people provided the opportunity to apply psychological skills and knowledge' and 73% responded 'yes' to the item 'it's necessary to respond differently and with a modified approach to older people'. When asked, 'if yes, what factors need to be taken into account?', the most frequently reported was 'cognitive decline' (28%).

Laidlaw and Pachana (2009) call for further research into the attitudes, motivations and experiences of practitioners working with older people, so that they can be better equipped with the knowledge and skills required to work flexibly with this diverse and

demographically shifting population. Trainee clinical psychologists are an important group in this respect, as experiences during training may have an influence on their future career choices and development. Interpretative phenomenological analysis offers a method for focusing on understanding participants' individual experiences and has been used in previous unpublished clinical psychology doctoral theses exploring trainee clinical psychologists' experiences (Wigg, 2009; Mills, 2010; Begum, 2012; Peacock, 2011).

2.2.1 Rationale

There have been no previous qualitative studies investigating trainee clinical psychologists' experiences of working with older people. Trainee clinical psychologists deliver psychological therapy to older people who are experiencing significant emotional distress. They develop close, professional relationships with clients, drawing upon skills and knowledge gained both within Older Adult (OA) placements and more broadly from across the training course. Trainee clinical psychologists and recent graduates provide a valid focus for the present study, as they are at a point in their career development which is highly relevant to future clinical psychology training. Trainee clinical psychologists' experiences may give further insight into unique aspects of clinical work with older people, which potentially may be of relevance both to teaching on clinical psychology training courses and to aspects of clinical placements. Previous research using postal surveys (Lee et al., 2003a; Lee et al., 2003b) whilst important, lack the depth of qualitative approaches. The present study therefore aims to build upon existing research by exploring trainee clinical psychologists' experiences in depth, using open-ended questions in semi-structured interviews.

2.2.2 Aims and research questions

The aim of the present study was to explore trainee clinical psychologists' lived experience of working with older people.

2.3 Method

2.3.1 Design

A qualitative research design was adopted based upon the study's aim. Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate method as it aims to get close to the lived experience of participants in depth (Smith, Flowers & Larkin, 2009).

2.3.2 Ethical approval

Ethical approval was granted from Coventry University (see Appendices E & F) where the research team is based. Ethical approval from Coventry University was considered appropriate by the local NHS Research and Development Team (see Appendix G).

2.3.3 Procedure

2.3.3.1 Phase 1: Focus group

A focus group was conducted with trainee clinical psychologists with prior experience of an OA placement, in order to develop the interview schedule for the individual semi-structured interviews in phase 2 (see section 2.3.3.2). The objective of the focus group was to use the themes to inform the interview schedule for the semi-structured interviews. Trainee clinical psychologists in their final year of training were invited to take part in phase

1 of the study by email (see Appendix H), which included a participant information sheet (see Appendix I). Four participants contacted the researcher. The focus group took place at a convenient time and location for all four participants, and they were given an opportunity to ask questions about the study before signing a consent form (see Appendix J). Participants were asked four open questions (see Appendix K). The focus group was voice recorded and lasted approximately 35 minutes. The researcher completed thematic analysis of the focus group transcript (see Appendix L), following the steps outlined by Braun and Clarke (2006).

2.3.3.2 Phase 2 – Semi-structured interviews

2.3.3.2.1 *Materials*

The interview schedule for the semi-structured interviews (see Appendix M) was constructed using the focus group themes (see Appendix L). The interview schedule was reviewed by the researcher's supervisors and was piloted in one practice interview with a trainee clinical psychologist, which was not subsequently used in the analysis. Subsequent amendments were made following feedback. The interview schedule was constructed taking into account specific issues likely to arise in IPA, for example prompting questions and an initial question to establish context and facilitate rapport (Smith, Flowers & Larkin, 2009).

A demographic questionnaire was developed, in order to obtain additional demographic information from participants (see Appendix N).

2.3.3.2.2 Recruitment

Participants were recruited from two West Midlands clinical psychology training courses. Gatekeeper permission to contact clinical psychology trainees and recent (2013) graduates was granted by the course directors (see Appendices O & P). An invitation email (see Appendices Q & R), including a participant information sheet (see Appendix S), was then sent to potential participants via the course administrators. Potential participants who contacted the researcher were given an opportunity to ask questions via telephone or email and the researcher checked that they met the inclusion and exclusion criteria (see Table 2.1 below).

Table 2.1 Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Completed at least 12 weeks of one training placement where at least 50% of the direct clinical work was with older people (aged 65 or above). Placements could be in older adult, neuropsychology, physical health or other, provided they met criteria 1. Placements completed within the last 18 months.	Less than 12 weeks of placement completed. Less than 50% of direct clinical work with older people. Placement with older people completed more than 18 months ago.

2.3.3.2.3 Participants

In total, eight participants were recruited to the study. A summary of participant characteristics is presented below (see Table 2.2).

Table 2.2 Participant characteristics

Category	Demographic Information
Gender	7 Female, 1 Male
Age	Mean: 28.25 (range: 23-35 years)
Ethnicity	6 White British, 1 White Irish, 1 Mixed / Other Mixed
Type of placement	6 Older people's mental health, 1 Physical Health, 1 Neuropsychology
Stage of training	1 – in 1 st year of training, 4 – in 2 nd year, 2 – in 3 rd year, 1 – recently qualified
Prior experiences of work with older people	4 – None 2 – 1 Assistant Psychology post (8 months & 15 months) 1 – 2 Assistant Psychology posts (6 months & 12 months) & Research Assistant (6 months) 1 – 1 Assistant Psychology post (2 years), Groups Programme Project Manager (8 months)

2.3.3.2.4 Interview procedure

One-to-one in depth interviews were conducted between December 2013 and February 2014. The researcher met with participants at a mutually convenient date, time and place. Participants were given a further opportunity to ask questions about the study, and were then asked to sign a consent form (Appendix T) and complete the demographic questionnaire (see Appendix N). The interview schedule (see Appendix M) was used flexibly by the researcher as a basis for the interview. The schedule included specific questions which were covered in all interviews, as well as follow up questions to elicit further information about individual participant's lived experiences. This is in accordance with Interpretative Phenomenological Analysis (IPA) guidance (Smith, Flowers & Larkin, 2009). The mean length of the interviews was 52 minutes. A digital voice recorder was used to record all the interviews.

2.3.3.3 Data analysis

The individual interviews were transcribed in full by the lead researcher and then analysed using IPA (see Appendices U & V for an example of data analysis and emergent themes for one participant). The stages of analysis completed by the researcher are summarised below (see Table 2.3) and based upon guidance from Smith, Flowers & Larkin (2009).

Table 2.3 Stages of analysis completed by the lead researcher

Stage	Description
Writing in the reflective diary	Notes were made in the researcher's reflective diary after each interview.
Transcribing	The recorded interviews were transcribed by the researcher as soon as possible following each interview.
Reading	The transcripts were read and re-read whilst again listening to the interview at least once all the way through ² .
Commenting	In the right hand column, descriptive, linguistic and conceptual comments were made on each interview transcript.
Noting emergent themes	In the left hand column, emergent themes were noted on each transcript.
Collecting themes	Themes for each participant were collated on post-it notes and connections between themes were established.
Merging themes	A search was made for patterns across participants' themes. Themes were merged and documents of relevant extracts from all participants were created for each superordinate theme, to provide a check for internal consistency, and appropriate changes were made.
Taking it deeper	The level of superordinate themes and themes were checked – those at the descriptive level were re-considered at the interpretative level.

² The table of stages for the IPA analysis was not entirely linear. Noting was made during initial reading. The transcript was read or listened to again following commenting or noting of emergent themes. The reflective diary was used at different stages as necessary. A focus on 'taking it deeper' was used throughout the analysis and particularly in the final stages. Transcription, commenting and noting emergent themes were completed as much as possible before conducting the following interview.

2.3.3.4 Reliability and validity

A bracketing interview was conducted by one of the researcher's supervisors with the researcher, using the interview schedule. This was used to reflect on the researcher's own experiences, not with the aim of bracketing off the researcher's own position completely, but as an opportunity to enhance researcher reflexivity.

The researcher is a current trainee clinical psychologist studying on the same clinical psychology course as five of the phase 2 study participants. However, the researcher did not have any prior relationship with those participants.

Inter-rater reliability was established through a peer IPA researcher who analysed 10 pages of one transcript (20 minutes of one interview) to compare comments and emergent themes. The analyses converged and did not reveal any missing comments or themes. In depth discussions with supervisors about emerging themes helped to guide the researcher throughout the analysis process and acted as an additional reliability check.

2.4 Results

IPA analysis led to the emergence of three superordinate themes and within each superordinate theme there were three subordinate themes. These are listed in the table below (see Table 2.4).

Table 2.4 Superordinate themes and subordinate themes

Superordinate themes	Subordinate themes
Theme 1: Hearing people's stories	Power of giving time and space Reflections on the richness of life Giving hope and optimism
Theme 2: Reminders of mortality	Close to home Not long left Distancing from self
Theme 3: Overcoming challenges to the professional role	Accepting what you can't change Understanding how clients relate to me and to psychological approaches Seeing value in what I do

2.4.1 Hearing people's stories

The importance and value of "*hearing people's stories*" (George, L30) was evident in participants' accounts. Harry said, "*the most enjoyable thing was sort of being able to hear all of their life stories*" (L290). Others talked about the "*life story*" (Sam, L567) and the word 'rich' was used to describe the life experiences of their clients. Alongside these life stories, were stories of present difficulties; stories of change, resilience and optimism.

2.4.1.1 Power of giving time and space

The 'power of giving time and space' was evident: "yeah [emphasis added] *time and space*" (Andy, L231). The awareness of its importance provided participants with a sense of power in their ability to make a difference in people's lives, "*I guess it felt like it was in my power to offer quite a bit*" (George, L91). George valued listening despite not being able to 'fix' or change things for the client. Jamie talked about the 'power of giving time and space' for a bereaved older client to grieve. Andy, Jamie and George used the word 'just' to precede

'time and space' and 'listening'. Despite recognising its power, they tended to minimise their own skills, and suggested that it was an easy process.

Participants may be more likely to continue to give time and space, after receiving direct feedback from older clients about its benefits:

[They] *were very appreciative of the work and time that you'd spend with them, more so than other client groups.* (Sam, L51)

Sam's use of the word "*rewarding*" (L27) and Andy's use of the phrase "*I really, really valued*" (L555) convey a reciprocal relationship, so that 'giving time and space' has an impact for both client and therapist.

Participants also referred to the 'power of giving time and space' for people with possible dementia. Andy talked about a tension between gathering sufficient information for an assessment, and offering time and space, "*You've got someone who actually is really struggling and...there's a story behind that*" (Andy, L82). Sam talked about the importance of time and space post-diagnosis, having seen clients and their families 'in pieces' and said, "*they need...at least a couple of sessions to talk this through*" (Sam, L161).

Recognising the 'power of giving time and space' was valued by both participants and the older people they worked with, across a range of settings and presenting difficulties, particularly when emotions required time and space to be expressed. Some participants also had supervisors who emphasised its importance.

2.4.1.2 Reflections on the richness of life

Participants' 'reflections on the richness of life' included appreciating the number of years that a couple had been together and what had happened in clients' lives. The richness of older people's lives appeared to enrich participants' understanding of life.

Participants talked about the rewards of working with this age group, which brought a new perspective. Older clients' lives were both interesting for participants to hear about, *"it was nice work for me to do...to see what a history they'd had"* (Jamie, L856) and valuable to the older people who *"were able to say 'gosh like look what I've achieved and look what I've done'"* (Jamie, L797).

Participants' experiences of hearing these stories led to increased understanding of the wealth of experience in clients' lives. They were happy to bring this exploration into the therapy, as it provided insights into the development of clients' difficulties. One participant showed that she gained from hearing stories and saw herself as fortunate:

A lot of people have lived through a war, one of my clients had been evacuated to Canada, her ship had been torpedoed, I think you're just sort of listening and I think goodness me what a rich life and I'm really privileged that you're...telling me this. (Sam, L252)

George *"quite liked hearing stories of... (laughs) years gone by...it made me kind of reflect a lot on changes in society I guess, and what was good and what was bad about that"* (L682).

Stories had the potential for providing participants with opportunities to reflect on life outside of their professional role, in addition to the relevance of stories in therapy.

Although not all participants communicated 'reflections on the richness of life' in their accounts, as the quotes demonstrate, those who did conveyed their fascination and sense of privilege.

2.4.1.3 Giving hope and optimism

Participants described the positive impact that the work had on them, and 'giving hope and optimism' in particular came directly from hearing people's stories. Participants expressed prior negative expectations of the work, but by the end the majority of participants were optimistic. Sam's statement captures this change, *"At the moment I feel like my ideal job would be with older adults, so yeah...like a convert! (laughs)"* (L689). Alex also expressed how working with older people in therapy has *"given me more hope for old age"* (L650), specifically through hearing clients' stories of change.

For one participant, older people also communicated a hopeful story in their demeanour, with *"a smile on their face"* (Jamie, L1082), despite the challenges of living with a chronic health condition.

Harry and Andy described setting up groups for people with memory problems and their carers. Both talked about how they most valued the group members' contributions over anything that they could provide themselves. The stories of resilience and the importance of shared stories among group members came across in the participants' accounts:

The humour that they come with (laughs) and again that resilience that they've...brought to the group and kind of the support that they gave each other...was just really lovely to be a part of, it felt an honour actually. (Andy, L199)

Another participant listened to stories and was given inspiration for how to lead her own life:

I can remember coming away (laughs) thinking 'oh I need to be more thrifty'....it sounds daft but there was something a little bit kind of, inspirational in kind of, some of the stories that they told. (George, L715)

Participants showed respect for the lives that older clients had lived. Stories of achievements and resilience elicited admiration and humility, 'giving hope and optimism'. Conversely, one participant felt hopeless about working with older people and as a result, did not think she could work in this area.

2.4.2 Reminders of mortality

Participants described working with older people as a reminder of *"quite a lot of my own...thoughts around death and things like that, makes it...kind of your own mortality and your, you know, friends and family's kind of mortality"*. (Andy, L732)

2.4.2.1 Close to home

The concept of *"close to home"* (George, L522) relates to how issues raised around mortality could not be separated from the participants' own lives. Harry talked about older

people's life experiences as *"something that I might go through myself or my partner or my family members"* (L376).

Lou was brought closer to her own hopes for the future, *"I want to be a well old person"* (Lou, L342) but having heard clients' unfulfilled hopes of retirement, then also questioned this, *"you think well actually you don't know what's going to happen and what if I'm not well enough to do it all then?"* (Lou, L346).

Alex, empathising with older clients' experiences of still feeling the same on the inside but their bodies are ageing, explained that *"it certainly made me think about myself. Just about well hmmm...what would that be like?"* (Alex, L517). Both Alex and Lou used rhetorical questions to contemplate their own future lives. Jamie also does this when empathising with a bereaved client:

Sometimes I would come home and say to my boyfriend 'oh it's so sad, is that going to happen to us?'...it got me thinking about like way, way in the future, um, and kind of yeah, 'what if I ever lost you?' (Jamie, L1031)

Sam, on witnessing older clients' distress and anger at the possibility of losing their driving licenses, changed her view on the importance of her husband learning to drive now, *"actually if you've never driven it's never going to hurt"* (L406), and is opposed to a home in the countryside in the future:

At the moment it's definitely made me feel very strongly, no. It's good to be...in an infrastructure where there's public transport. (Sam, L412)

Older clients' physical characteristics, personality and background brought one participant 'close[r] to home', *"reminds me of my uncle"* (Chris, L445). When clients came from the same county *"it...hit home a little bit more...they're usually the people that I was affected by the most really...so I'd talk about it...in supervision"* (Chris, L407).

Ageing as 'close to home' was also viewed positively, *"that's going to be me one day as a carer and hopefully as an old person"* (Sam, L450), and was associated with rich lives to be led, *"working with older people...did make me think about my life and 'what am I going to achieve?'"* (Jamie, L510).

Participants' experiences of being brought 'close to home' included situations when they were reminded of their own lives and loved ones, in the past, present and future.

2.4.2.2 Not long left

Participants were aware of older clients' mortality, including those with physical health problems, *"being aware that yeah, they didn't have long left"* (Jamie, L908), as well older people more generally, *"there's not as much looking forward as there may be for a working age adult"* (Andy, L710).

Andy talked about clients with serious health conditions and described the awareness of approaching death as 'uncomfortable':

When they're talking about their future and kind of saying, 'oh, you know, I might drop dead tomorrow'...it's a real, real prospect...it's quite, I don't know, I find that quite uncomfortable, yeah tricky thing to kind of sit with. (Andy, L727)

Alex suggested that conversations about death and dying were frequent and difficult in nature, *“something that is difficult...that I found...comes up quite a lot is...issues around sort of mortality”* (Alex, L476), and described seeking support in supervision to facilitate such conversations.

‘Not long left’ was also relevant to the dementia process, most poignant when participants described their clients as *“[having] insight into what was going on”* (Sam, L64). The phrases *“one way street”* (Sam, L66), *“declining condition”* (Chris, L279), *“managing decline”* (Alex, L833) and *“downhill”* (Chris, L281) were used when talking about how sad and difficult dementia diagnoses were.

Andy and Alex contemplated what the future may hold for people who receive dementia diagnoses, having had prior experience of working with people in more advanced stages of dementia and *“understanding the changes that are inevitably going to take place”* (Alex, L759):

I guess...you’ve got an idea of how things might deteriorate...I guess we sometimes, we see worst case scenarios I guess and I don’t know, it’s just, I think it’s just quite, quite sad, so I think that’s probably the most difficult. (Andy, L388)

Within the subtheme ‘not long left’, participants conveyed both realistic awareness of mortality, as well as discomfort and sadness about the inevitability of death and changes in clients’ lives through ill-health.

2.4.2.3 Distancing from self

Participants explicitly acknowledged difficulties in ‘distancing [work with older clients] from self’, and were seemingly impelled, consciously and unconsciously, to create psychological distance between themselves and the older clients.

Harry said, *“it’s difficult to dist...I found it difficult to distance myself from it”* (L267), whilst other participants compared the work to different clinical specialities, where it was easier to distance themselves, *“I know I could have a child with a learning disability or I could have a brain injury...but it’s not certain, whereas becoming old is much more certain”* (Sam, L490).

Further ‘distancing from self’, such as *“it’s not something I need to worry about quickly”* (Lou, L844) and *“I’m a long way off that”* (Jamie, L901), was evident in the interpretative analysis of participants’ accounts, and may have been unconscious. In contrast, George consciously described a need to *“do daft things just to kind of get in touch with your youth”* (L480) when working with older people:

I can’t describe it very well other than I was really aware sometimes of...having like impulses to...play my music really loud in the car on the way home and drive really fast...I don’t know, something...(laughs) to remind myself that I’m young and I’m able. (George, L404)

Whilst not as immediately obvious, participants may have unconsciously used language, such as *“death anxiety”* (George, L395, L524, L661) to create distance from its meaning. As

well as this clinical term, two participants use an informal phrase 'the end' instead of 'death'. For example, *"oh ok is that kind of how, how life is at the end?"* (Jamie, L901) and *"I don't really like to think about the end bit do you? (laughs)"* (Andy, L408).

A participant who did use the word 'death', also employed more ambiguous language in the same sentence, *"what will happen when I'm older...that kind of thing...death I suppose...it's those things...it's quite challenging to think about those things"* (Harry, L376).

Harry's statement also provides some explanation of why participants may distance themselves from mortality and death, because it is 'challenging to think about'. It also suggests a reason why participants may distance themselves both consciously and unconsciously from the reality of ageing and death.

2.4.3 Overcoming challenges to the professional role

Within this superordinate theme, three subordinate themes captured how participants were 'overcoming challenges to the professional role'. Participants were at various stages of accepting and understanding such challenges (subordinate themes: 'accepting what you can't change', 'understanding how clients relate to me and to psychological approaches'), and seeing beyond challenges (subordinate theme: 'seeing the value in what I do').

Challenges to the professional role included potential restrictions on participants, preventing them from working in the way they had expected. Challenges from older clients included the unchanging or worsening nature of some presenting difficulties, such as physical health problems, as well as different expectations of therapy, the therapeutic

relationship and the role of psychology. For example, George described thinking *"what am I doing here? This isn't a psychology job! (laughs)"* (L129) but still *"helped [the client] out because she couldn't physically do it"* (L130). Challenges also included being faced with differing opinions from colleagues and services about psychology's professional role, when 'seeing the value in what I do' and explaining it became more important.

2.4.3.1 Accepting what you can't change

Participants experienced sadness at the fact that *"there's a lot that you can't change and you can't fix"* (George, L43) and seemed to be at different stages of accepting what 'you can't change'. Lou seemed to find it harder to accept and work with, *"some stuff is so out of your control...like how can you work therapeutically with someone when you can't change their circumstances?"* (Lou, L436). George used the term *"insurmountable blocks"* (George, L652) and said *"there's kind of more of that than there are in other services maybe, but not necessarily"* (George, L657).

'Accepting what you can't change' was related both to circumstances which were impossible to change, *"can't bring someone's husband back from the dead"* (Lou, L436), and psychological patterns which clients were not ready to change. For example, Alex questioned *"how much do you challenge someone? ...or just support them with managing the position that they're in because that might be a safer or better place for them (laughs)"* (L680). Alex seemed to be thinking this through, using a rhetorical question, which implied there was a process of learning whether to challenge or accept.

Participants talked about managing their own feelings and expectations, which have the potential to get in the way of 'accepting what you can't change'. Andy's experience provided some evidence of this, *"I think certainly as a trainee...you want quite big shifts to make it feel like you're kind of making a difference and kind of getting somewhere"* (Andy, L298). However, small shifts were also referred to as *"worth it"* (Andy, L303) and *"worthwhile"* (Sam, L583).

Jamie questioned *"who do we want them to change for actually?"* (L249), whilst empathising with clients: *"I think some of them didn't...didn't feel the need to change and weren't motivated to change actually so, a lot of the time you had...kind of had to go with that"* (Jamie, L211). She conveyed a difficulty in reconciling 'accepting what you can't change' with her own hopes and the expectations of the professional role:

I can't help with this and...that's what I'm here for, I'm here to help...that's actually the main thing that's going to make a difference for them...I can't make a decision for them, I can't influence that decision. (Jamie, L943)

Lou also shared these expectations of *"really wanting to do something to help"* (L117) and *"didn't want her to just kind of leave, without having been helped at all really"* (Lou, L119).

This may be related to how participants felt when clients do not want to accept help:

I felt quite inept...that it was something about me...I couldn't get this man to talk...um so it was something to do with...it was my fault somehow. (Chris, L124)

'Accepting what you can't change' seemed to be a process of participants working within the confines of what is possible, what older clients are ready for and minimising potentially unrealistic expectations of themselves.

2.4.3.2 Understanding how clients relate to me and to psychological approaches

Participants showed understanding of how older clients related to them in their role as trainee clinical psychologists, *"I think there's definitely an element for some clients that they're quite lonely and they enjoy having someone to talk to"* (Sam, L44). Participants used that understanding to influence the way they worked and any consequent challenges to their role were attended to in supervision and through the use of boundaries. For example, Sam demonstrated both the importance of allowing time for *"some chat"* (L295) whilst also being *"quite tough....not just [emphasis added] being someone to have a nice chat with"* (L47).

Participants talked about older clients relating to them in different ways. Descriptions of *"a much younger person"* (George, L617) and *"their granddaughter's age"* (George, L620) were contrasted with *"the professional"* (Andy, L434) and *"[putting you] in an expert role"* (Harry, L385). This influenced how participants then related to the older clients, with *"a different sort of respect"* (Andy, L449) for those who had *"learnt a lot more of life's lessons"* (Chris, L506). Chris gave an example of how some clients related to her:

Just thinking about how...they might view me...a young...woman who just wanted to talk about feelings (laughs) and you know for some men that was...just, 'Go away. What do you know love? You don't know anything'. (Chris, L497)

Participants also talked about the ways in which older clients and their families related to psychological approaches, *“they assume you’re going to give them some kind of pill or some kind of easy solution”* (Harry, L412), *“there’s an assumption [by relatives] that psychology can be done to them...they should [emphasis added] have psychology”* (Alex, L463) and *“sometimes they’ve come because someone else thinks they should”* (Lou, L973).

However, participants also learnt to be open to changes in the way older clients related to psychological ideas, *“when given the opportunity there’s a lot of feelings and emotions there”* (Andy, L465). Sam recognised that older clients have to learn a *“different language”* (L29) and explained *“as the placement went on, we started to reap the rewards of that and...they did become more psychologically minded”* (L27).

Lou used the expressions *“massive sweeping generalisation”* (L974), *“my...assumption and stereotype”* (L975) when she said older people *“aren’t as psychologically minded”* (L976). Despite recognising that *“you do get that in adult services as well”* (Lou, L979), the preceding phrase *“I guess”* and use of the word *“but”* suggest that she did experience differences when working with older people.

There were varying ways in which participants ‘[understood] how clients [related] to [them] and to psychological approaches’. Some of these were evidenced through direct quotes from older clients, as remembered by participants. Whereas other ways that older clients related to them, *“they would put you in”* (Harry, L385), *“being pushed into”* (George, L628), were based upon how participants remembered feeling.

2.4.3.3 Seeing value in what I do

Participants 'seeing the value in what [they did]' was important, both when questioning their professional role, and having it questioned by others. 'Seeing the value in what I do' was recognised despite the limits of psychological therapy:

This person may never be free of anxiety...the fact that they've got an understanding of their problem has caused a few things to shift and...they feel a bit better about themselves.
(Sam, L584)

Following initial unease about conducting cognitive assessments, *"ticking that dementia box or not...felt too concrete, and while that is useful in some aspects...it just didn't...sit comfortably with me"* (Andy, L73), 'seeing value in what I do' relied upon feedback from older clients, *"I was surprised that...people I worked with found it quite positive if that makes sense?"* (Andy, L366), *"I've...come to terms with doing assessments...partly because I've heard from them...actually how useful it can be...having time to be told what it means"* (Andy, L563).

Another participant witnessed indirect feedback through the relief they observed:

A concrete answer for why they're having difficulties or why their family were having difficulties which to some was a relief to have an explanation and that they weren't going mad. (Sam, L135)

As well as providing an answer, participants talked about the importance of supporting people following assessment. 'Seeing value in what I do' was recognised in the provision of

follow up sessions or written reports, including *“accessible things for the client and family”* (George, L287), *“recommendations”* (Andy, L335) and *“identifying their strengths”* (Sam, L135). For Sam, *“post-diagnostic counselling always felt a little bit naughty because our service didn’t really like it”* (Sam, L157) but seemed necessary in order for Sam to be able to *‘[see] the value in what [she did]’*.

‘Seeing value in what I do’ also required clarifying the role of psychology: *“to look at...how the team is working...how people could...improve their skills and approach towards some older people”* (Chris, L602), *“my role there was also to...be a therapist and to sit and help talk to people and so that was why I would sit down and talk to people”* (Chris, L642). Chris wanted to challenge those dismissing the role of psychology, including the view of colleagues:

‘This is what we do, we work really hard, we make sure these people are fed and you know the basic needs are met and all you do is sit...and talk with them’ (laughs). (Chris, L570)

‘Seeing value in what I do’ was important to participants, requiring recognition of both the potential and limits of the psychology role. It was enhanced by positive feedback from older clients. This subordinate theme also highlighted a need to communicate the role of psychology to others, including colleagues, so that they could see the value in participants’ work.

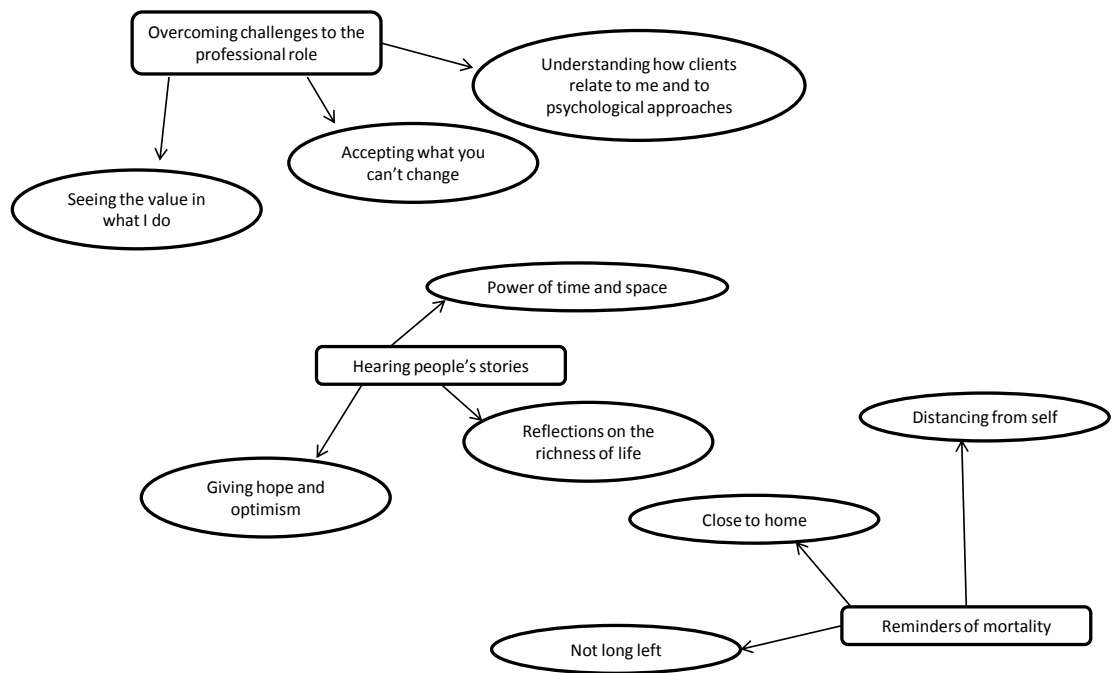
2.5 Discussion

2.5.1 Summary of results

The aim of the present study was to explore trainee clinical psychologists' lived experience of working with older people. Three superordinate themes emerged from the interview data: 'Hearing people's stories', 'Reminders of mortality' and 'Overcoming challenges to the professional role'. The three superordinate themes will be explored, including their inter-connections and relation to the existing literature. The study limitations and clinical and research implications will also be considered.

'Hearing people's stories' was important to the other two superordinate themes and therefore is placed in the centre of Figure 1 below.

Figure 2.1. A diagrammatic representation of the superordinate and subordinate themes



'Hearing people's stories' was an enjoyable aspect of the work for seven of the eight participants. It was considered essential for developing a therapeutic relationship with older clients and was also seen as valuable for the participants themselves. One participant questioned whether stories benefitted the client or were more interesting for the trainee. Another participant described unintentionally upsetting an older client after asking questions about the past. 'Hearing people's stories' was in most cases valuable, both in therapy and in cognitive assessments, including past and current strengths, difficulties and

achievements. The 'power of time and space' may contrast with structured therapy, and most participants felt that they had to be more flexible in therapy with older people, even when setting an agenda.

Participants were at different stages in 'overcoming challenges to the professional role', and for all three subthemes, there seemed to be a process of learning during the placement. For the participant who did not want to work with older people in the future, overcoming the challenge of 'accepting what you can't change' did not feel possible. The subtheme 'accepting what you can't change' relates to participants managing expectations of themselves and of older clients, including the understanding that chronic illness, bereavement, loss and death are not within their control. The subtheme does not refer to accepting 'no change' when change is possible. There seems to be an important balance in recognising when change is wanted by clients and is possible, and at the other end of the spectrum, when overemphasis on change may be either disappointing or even harmful both for clients and trainees in undermining their efforts and the significance of other helpful factors.

'Reminders of mortality' was not necessarily a negative aspect of working with older people, as the same participants also expressed their enthusiasm for the specialty. Although all noticed that the work made them think about their own ageing and mortality, for the majority of participants, it was not as hopeless as they had anticipated. This might be explained in part by hearing the stories of older clients' resilience via the subthemes 'giving hope and optimism' and 'reflections on the richness of life'. These two subthemes

may also explain some of the mechanisms by which participants are 'distancing from self' the 'reminders of mortality', by focusing on life stories rather than on ageing and death.

'Reminders of mortality' in the present study, provides further support for existing research on death anxiety. For example, among college student participants, there is evidence to suggest that reading descriptions of older people with dementia evoke more death-related thoughts than reading descriptions of younger people with dementia (O'Connor & McFadden, 2012). Middle-aged as compared to older people have been found to be more likely to avoid death and death related material (De Raedt, Koster & Ryckewaert, 2013). 'Terror Management Theory', which suggests that younger people associate older people with mortality (Martens, Goldenberg, & Greenberg, 2005) may be of relevance in attempting to account for these findings.

'Hearing people's stories' may be a way to manage both the 'reminders of mortality', as described above and in 'overcoming challenges to the professional role'. It appears to help with 'seeing the value in what I do' through hearing clients' stories of service experiences. Listening to older clients also helped participants in 'understanding how clients relate to me and to psychological approaches', and 'accepting what you can't change', facilitating time and space within sessions, for example for clients to make their own decisions and to express their thoughts, feelings and fears about psychological therapy.

2.5.2 Clinical Implications

The value of 'hearing people's stories' may have implications for older people's teaching on clinical psychology training courses. The importance of 'hearing people's stories' is essential

to understanding each older client, whatever therapeutic approach is used, and a range of approaches were used by participants. 'Narrative therapy', mentioned by two participants in the present study may be one way of using narratives or stories more explicitly in the therapeutic work with older people (White & Epston, 1990). However, it also seems that there is an important implication for flexibility with the role.

In terms of 'overcoming challenges to the professional role', it seems that participants need to go through a process of 'accepting what you can't change', and be able to see the value in the work despite not being able to change illness, ageing or the inevitability of death for clients. Perhaps trainee acceptance, managing their own expectations of both themselves and clients, is a prerequisite for facilitating client acceptance, and this may be facilitated on training course and by supervisors on placements. In order to support future trainee clinical psychologists in 'Understanding how clients relate to me and to psychological approaches' research on older people's attitudes could be introduced. Older people who have not previously accessed mental health services have been found to have more negative attitudes towards mental health problems, which may reduce new referrals for psychological therapy (Quinn, Laidlaw & Murray, 2009). However, each older person is different and views of mental health may change as new generations reach old age.

"Reminders of mortality' may have some relationship with death anxiety, which according to Terror Management Theory is associated with ageist attitudes (Martens, Goldenberg, & Greenberg, 2005). A consideration of death anxiety will be an important implication in clinical work, both in direct work with older people and in service improvements to care environments. Ageist attitudes influence communication by professional caregivers within

care homes towards the older people receiving their care (Lagacé, Tanguay, Lavallée, Laplante & Robichaud, 2012). This is both noticed and unchallenged by older people, which the authors suggest reinforces this pattern. Ageism may be hidden due to this perpetuating cycle, and future clinical work will require more open conversations about ageism within caring environments.

The reminders of mortality that were experienced by all participants may deter some people from working in the specialty. The inclusion of 'middle aged adults' in a recent study suggests that some of the present study findings on 'reminders of mortality' and 'distancing from self' may be relevant for both trainee and qualified clinical psychologists (up to the age of 50), as well as other professionals working with older people (De Raedt, Koster & Ryckewaert, 2013). This study, along with the present study findings, provide evidence of avoidance of death related information. This has implications for talking about death and dying in clinical work, which may not be sufficiently addressed within psychological therapy with older people. Continuing consideration by psychologists of these implications for both psychological therapy and within wider older people's services will be important.

2.5.3 Limitations

The present study provides a qualitative account of eight participants' lived experiences; utilising a small sample size as recommended in IPA research (Brocki & Wearden, 2006). Although a small sample was necessary and provided in depth data, the findings cannot be generalised to other trainee clinical psychologists. Another limitation of the present study is the absence of participant feedback (Elliott, Fischer, & Rennie, 1999) following the

analysis stage, which would have provided a further validity check. It is possible that the study may have been limited by attracting only trainee clinical psychologists who were interested in work with older people. However, one participant in particular was not interested in future work with older people. Participants planning their own qualitative studies may have been motivated by the opportunity to experience being an interviewee. Therefore, this may have broadened the range of research participants and be a potential strength of the study.

2.5.4 Recommendations for further research

The growing population of older people in the UK means that increasingly more professionals should be working directly with older people. Therefore further research in this area should help prepare professionals for working with this group. Other health professionals, such as nurses, could be interviewed about their experiences of working with older people. As age independent services are becoming the norm after recent changes in NHS trusts, this work will not be limited to older people specialists. Therefore it may be important to understand the experiences of other professionals, including clinical psychologists, primarily working in other specialisms and now increasingly required to work with older people.

Within the subordinate themes, 'seeing the value in what I do' and 'giving hope and optimism', two participants talked about their experiences of running a group for people with mild memory problems and how important it was to share their experiences and learn

from each other. This could be further explored in future research, to understand the experiences of people with dementia and their carers who attend such groups.

There appears to be no existing published research on older people's experience of psychological therapy using a qualitative approach. This would provide further insights into the other side of the story, including how trainee or qualified clinical psychologists are experienced by the older people and their relatives receiving their services. In addition, 'seeing the value in what I do' meant participants being aware of the views of colleagues. Therefore colleagues' experiences of working with psychologists may also be a valuable and informative area of research for future service development.

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Chapter Three: Reflective Paper

“Hearing people’s stories”: A story about my research

This paper has not been prepared for submission to a journal.

Overall chapter word count (excluding references): 3,561

3.1 Introduction

My recently completed research on trainee clinical psychologists' experiences of working with older people led to the emergence of three superordinate themes, one of which was "hearing people's stories". This theme, described by participants in my study, evoked a strong sense of respectfulness for older people's lives and experiences. Learning about the importance of this theme from the participants in my study has led me to explore the concept of 'stories' in human life and in therapeutic work, both generally and with older people in particular. In addition to this, I have also been reflecting on how the qualitative research process could be seen as a way of "hearing participants' stories". Therefore this will also be a space to consider how their stories were heard by me and may be heard (in a condensed form) by those who read my research. Furthermore, in writing this reflective account, the reader will also be "hearing my story" of the research process.

3.1.1 Stories³

"Hearing people's stories" has allowed me to make a link between the older people that participants were working with, the participants themselves and me as the researcher. Once I started thinking and reading more about this theme, I noticed this connection readily, increasingly recognising the importance of stories to all of our lives. Turner (1996)

³ Throughout the essay I will use 'story' and 'stories' to refer to a variety of situations where someone is speaking or writing about their own experience, including therapeutic sessions and research participants' accounts.

argues that story, or more specifically parable (a combination of story and projection), is the root of how the human mind processes and organises information and experience. He suggests that the complex structure of language may have evolved from the use of story, a human instinct to convey meaning about the past, present and future, and provides evidence that stories are an efficient way of using our cognitive capacities to make sense of the world.

3.1.2 Metaphor

Metaphor is used frequently in parables and stories and is recognised as important in therapeutic work, including narrative therapy (Kropf & Tandy, 1998), acceptance and commitment therapy (Hayes, Luoma, Bond, Masuda & Lillis, 2006) and psychodynamic therapy (Bornstein & Becker-Matero, 2011), all approaches that were spoken about by research participants in their work with older people. Metaphor has been used in psychodynamic therapy for some time, and “metaphoric concepts connect ostensibly separate aspects of human experience, linking body and mind, emotion and memory, past and present, unconscious and conscious” (Bornstein and Becker-Matero, 2011). Metaphor can be used to understand and make sense of our lives through existing stories, such as myths and fairy tales (Campbell, 1969). However, new metaphors can also be used to help people tell their own story. One example of this is ‘the tree of life’, with the roots, branches, leaves and other elements representing family history, relationships, skills, qualities, hopes and dreams, and has been adopted in work with older people (Clayton et al., 2012).

3.2 Hearing older people's stories

One participant in my research study used the phrase “hearing people's stories” which seemed to capture both succinctly what other participants were saying about the work with older people, as well as being broad enough to apply in multiple contexts. For example, it applied to older clients coming for psychological therapy, those being assessed or having been diagnosed with dementia. In addition, stories provided benefits for both older clients, in being listened to, but also for the participants, in hearing about their clients' strengths and resources. Clayton et al. (2012) describe running a workshop with older people, using the tree of life as a basis from which to construct preferred identity stories, before discussing difficulties and then collaborating in exploring coping strategies. This approach recognises that stories can be about strengths and resources as well as painful emotions, trauma and difficulties. Reading this reminded me of two research participants describing the groups that they facilitated for people with dementia and their carers. They both talked enthusiastically about what the clients gained from hearing each other's stories rather than being taught specific techniques by trainee clinical psychologists.

3.2.1 Use of story with older people

The importance of story for people with dementia includes both understanding the facts of someone's life story, as well as the act of storytelling in itself. The importance of story in understanding someone with dementia, has been recognised in “Life Story Work” (Kaiser, 2012) as promoting personhood. A person who has dementia may have some difficulty in telling their story and may need to be helped by others, such as their closest relatives and

friends. Life story work has evolved as a consequence of this, recognising the importance of those who care professionally for people with dementia knowing about the life, work, interests and relationships of each individual. I was interested to read about the Life Story Network (Kaiser, 2012) an organisation which trains carers and staff working with older people to facilitate story-telling and enhance person-centred practice. Another way of recognising the importance of story, it places less emphasis on learning details about the life of the person with dementia, and more on storytelling in itself, including memories from the past. It recognises the value of storytelling as a conversation tool, as storytelling and reminiscing are abilities found to be retained among people with dementia (Fels & Astell, 2011). They highlight the need to empower people with dementia to tell their stories, relying upon an active listener to support the storyteller.

3.2.2 Dominant stories about ageing and older people

In writing this paper I have also considered dominant stories about ageing, including associations with disability, illness and frailty. In contrast to this, there is also a narrative about successful ageing, or ageing well, which has the potential to blame those who do not view themselves as ageing well or successfully (Hepworth, 2000). Both of these narratives have the potential to categorise, marginalise and to ignore the diversity among older people. Therapeutic interventions and social initiatives which open up ways of understanding the person, with their many different attributes and experiences will be important in order to challenge dominant narratives, and provide alternatives. Narrative therapy has been used with older people, both with and without dementia, to externalise problem stories and connect to preferred ones, by recognising exceptions and unique

outcomes (Banks & Ord, 2013). In a field related to clinical psychology, one drama therapist describes working with older people in group therapy, enacting new and existing stories (Crimmens, 1998). These role plays included older people as well as professional carers taking part as different characters, using props and their imagination, allowing them to see each other and themselves in alternative roles. In a recent study, medical students' attitudes towards people with dementia improved after participating in an intervention called TimeSlips (George, Stuckey & Whitehead, 2012), using pictures and improvisation to tell stories in the present. Improved attitudes included increased understanding of the creativity, imagination and emotional awareness of people with dementia.

3.3 Stories of the research: Hearing participants' stories

Hearing people's stories was also related to the type of research I was doing. I wanted to hear the stories of my participants, from their perspective, and hoped that I would create the right conditions for them to be comfortable enough to be open with me as the researcher. In the methodological approach I adopted, interpretative phenomenological analysis (IPA), participants "can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story" (Smith & Osborne, 2007, p. 59).

3.3.1 The story receiver: My experience and position

I felt privileged to hear the stories of trainee clinical psychologists in my study. I also developed a new interest in qualitative approaches to research, as it was the first time I had carried out a qualitative study. Participants' accounts were rich and varied and I

enjoyed meeting a variety of people, each with a story to tell. I wanted to do justice to their experience and therefore doing the analysis and choosing which quotes to use to best illustrate the shared and varying stories of my participants was challenging. For example, participants also had stories to tell about the services they worked in, how they were set up, and the benefits and constraints. However, as working with 'older people' was the focus of my study, rather than working with 'older people's services', I felt like important information that participants wanted to talk about was lost. It was hard to leave out these sections, even though they didn't answer my question. It was a difficult balance at times, listening to what participants had to say, and guiding them back to the research question when their answers strayed onto different topics.

My own position as a trainee clinical psychologist was important for me to consider, having completed one placement with older people in my first year, and being on another placement with older people during the period when I was conducting research interviews with participants. I found this helped to bring alive their experiences, thoughts and interests, as I could imagine them in these settings and could relate to what they were saying. Before I began interviewing participants, I was interviewed by my one of my research supervisors using my interview schedule (the bracketing interview; Roulston, 2010). I talked in depth about working with individual clients, including how the work had progressed and how it had made me feel. I was aware of the fact that I spoke quite specifically and in depth rather than more generally about the work, and I noticed this differed from the way some of my participants approached the interview. For example, some shared more knowledge and opinions about the work, their approach and their

values, and talked less about individual clients. I was aware of learning from and respecting the individual participants' responses to the questions, rather than assuming they would answer in a similar way to me.

Listening to experiences which I had also shared without saying anything about my own older adult placement felt strange at times and one sided. For example, asking "can you tell me more about that?" rather than "yes I know what that's like" or "it was a different for me". However, it was important that they didn't know my 'story' in order for them to be able to tell their own. Nevertheless, I noticed when listening back to the recording that I sometimes used 'yeah' as a minimal encourager, which may have sounded as though I agreed with what the participants were saying.

Despite not wanting to influence the stories of my participants, as fellow trainee clinical psychologists, there were, nevertheless, factors which may have influenced their accounts. For example, I was aware of myself as a third year trainee clinical psychologist interviewing other trainee clinical psychologists and of how it may have felt from their perspective. Some were more explicit about this, one saying that they felt bad making negative comments about work with older people as they assumed that it must be my area of interest. I found it easier when these comments were made because it meant that I could emphasise the importance of their perspective rather than my own. I was there to hear about what they had to say and I wasn't there to test their knowledge or judge them in any way. I felt as though some participants were conscious of our varying levels of training, and may have devalued or been under-confident about their own thoughts and ideas. It was

fortunate that these moments were rare and I emphasised the importance of their own experience and perspective.

3.3.2 Being the story teller

I wondered whether it was strange for participants, as trainee clinical psychologists, to be asked in so much detail 'what was it like for you?' as their work inevitably focuses on asking questions to others and listening to those individuals' stories: the stories of their clients. I recognised that it may have been difficult or sensitive for participants to talk from their personal perspective, but that this opportunity to share may have also been valued by them, as much as it was by me. One participant told me that being interviewed had been harder than she expected, as it raised difficult feelings which connected the placement with her personal life. Another participant said that she had enjoyed the interview as an opportunity to remember what had been learnt from the placement and to reflect on how it influences her work now.

There might be different avenues for telling a story, which may suit some more than others. For example, one participant spoke about deriving benefit from an assignment, completed after the placement with older people had finished, as a way of reflecting on the placement in depth, in a way that she did not have the opportunity to do in her usual work. Some participants also mentioned course-led 'Integrating Theory and Reflective Practice' sessions as an opportunity to hear about the experiences of their peers, some shared and some different from their own. This is one forum where hearing the stories of trainee clinical psychologists is encouraged, alongside making links to the literature. However, it is

in less depth than talking one to one with a researcher, using an IPA approach, and it is likely to be a rare and slightly unusual experience to talk for up to an hour about their own perspective and experiences. Some participants reflected afterwards that they had more to say than they had expected. Another had not known where to start when asked the first open question, and seemed to de-value her experience when describing it as 'limited'.

Some participants were interested in the IPA approach, having previously used or planned to use it in their own qualitative research. Being a participant in the study gave them an experience of being the interviewee, which could then provide them with insights for their own research; one participant particularly recognised this. This may have been beneficial to the research as those participants appeared to understand that I was interested in hearing about their experience in depth, and may have felt free to tell their story in their own way.

3.4 Unheard and untold stories

When stories of clients that participants had worked with might have been unheard, for example by family members or by professional carers, participants recognised the importance of providing opportunities for a story to be told. One of the participants talked about her experience of therapy as an opportunity for people to talk about topics which are too difficult to approach with their family members or friends. As therapists, it may be important to appreciate barriers for people in telling their stories and recognise there may be multiple stories, versions of which may be influenced by the story receiver, the story teller, the setting and time at which the story is told.

Loneliness has recently been a topic of interest in the media (Sample, 2014) and in my view, seems to be related to decreased opportunities for older people to tell their stories. Sample (2014) directed readers to a recent longitudinal study (Victor & Bowling, 2012) which found that improved physical health and social relationships were both associated with reduced levels of loneliness. Interesting initiatives, which I have recently read about in the media, may enable older people to increase social connections, which would in turn provide opportunities for them to tell their stories. For example, I recently heard about the “Speaking Exchange Project” (Heigl, 2014), which connects older people in nursing homes with Brazilian students who want to learn English over a video link. The “Good Gym” encourages people to participate in community activities whilst keeping fit, such as visiting isolated older people, who in turn become their “training coaches” (Barkham, 2012). These examples recognise that isolated older people may have reduced social opportunities. They also highlight mutual benefit and recognise what older people have to offer. These examples demonstrate the wide range of ways to increase inclusion. In addition, health services may also benefit from facilitating storytelling. For example, Clayton et al. (2012) provide an example of using a group format with older people which contributed to a sense of collaboration and community.

Along with other unheard or untold stories, positive stories may get lost and because they have the potential to benefit others, require further opportunities to be heard and told. For example, talks and written information by people with dementia can be used to help those newly diagnosed (Offord & Field, 2013). In addition, trainee and qualified clinical psychologists, as well as other professionals working with older people, may benefit from

hearing more stories of people living well with dementia. These stories, particularly if heard and witnessed directly, would provide real experiences of hope and optimism. The IPA analysis found that “giving hope and optimism” (one of the subordinate themes) was important to the trainee clinical psychologists that I interviewed. Other participants talked about finding the cognitive assessment process hard because of previous experiences of seeing people with dementia in the “worst case scenarios”. Trainee clinical psychologists’ fears about the dementia process could be unconsciously communicated to clients, both those being assessed for dementia and those recently diagnosed. Hearing and experiencing more stories of the ways in which people show their strengths, resources and abilities, could provide trainee clinical psychologists with more hope and optimism. In turn they could tell these stories to older clients themselves or provide clients with opportunities to hear these stories directly from those living well with dementia.

3.5 Personal Reflections

Stories come in all shapes and sizes, with varying messages to tell about human nature. They present differing views and experiences, as well as shared emotions and common goals. The importance of story is universal and inevitably I have, in the process of writing, also made links to stories in my own life. These are stories which I had previously taken for granted or been less aware of their significance. I was reminded of this recently when reconnecting with a relative and sharing stories of the past and present. I noticed the questions we asked each other, such as ‘what happened next?’ or ‘go back a second, and what did they think when he did that?’. These questions facilitated storytelling, getting to the detail, the chronological order of events, as well as communicating the relationships,

not only between those in the story, but also the storyteller and the story receiver. In another example, the psychoanalytic therapist that I see has recently made reference to fairy tales, such as 'The Wizard of Oz' (Baum, 1956) and W. H. Auden poems (Auden & Mendelson, 1976). Writing this paper has meant that I am now paying more attention to these literary examples, and thinking about broadening my own knowledge of folk tales, stories and myths, and their links to human nature and psychoanalytic concepts (Mitchell, 2010), which may in future provide me with additional ways of intervening with clients. It has also highlighted to me the benefits that I have gained from stories, having recently experienced my own loss. Hearing stories of others' losses has helped me understand, explore and process my own thoughts and feelings. If stories have been a resource for me, I believe they will be just as important for future clients. I am not suggesting imposing stories on others, but allowing them to tell their story in their own way and to choose the stories which speak to them.

3.6 Conclusion

It has been important for me to remember from the study I have completed, that there are multiple and varying stories to tell, those of strengths, positive experiences and resources, as well as difficulties, conflicts and challenges. On reading more about older people and the use of story, metaphor and narrative approaches, I have been inspired to learn more about how these can be used both in therapy and professional practice development among colleagues. For example, I have considered how telling stories may have helped the research participants, and have since wondered whether there could be further opportunities for both trainee and qualified clinical psychologists to share their stories.

These could be stories of research, clinical practice and could focus on their own experience or those of their clients. In order for this to be helpful it seems that similar principles to IPA would need to be applied, including confidentiality, a focus on the person's individual experiences, sharing these openly and honestly, with no right or wrong. I read a recent example of stories being shared, among contributors to a recent book called 'Being with Older People: A systemic approach', which inspired the content and focus of their writing. The telling, retelling and connecting of stories of older people, both personal and professional, are described and related to existing practice and literature (Fredman, Anderson & Stott, 2010). This conveys the relevance of sharing stories to develop ideas and concepts about clinical practice.

The superordinate theme "hearing people's stories", which inspired the present reflective paper, has led me to engage with a range of research, stories and insights which may have otherwise gone unexplored. I am grateful for the opportunity to have conducted this study, to the participants who shared their stories and to my research supervisors who encouraged me through their own stories of research. It has opened up a new way of thinking and communicating in and about stories, which I intend to hold onto and make use of as my career develops.

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Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

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9. Manuscript style

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11. Further information

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Appendix B

EBLIP Critical Appraisal Checklist

EBLIP Critical Appraisal Checklist		Yes (Y)	No (N)	Unclear (U)	N/A
Section A: Population	Is the study population representative of all users, actual and eligible, who might be included in the study?				
	Are inclusion and exclusion criteria definitively outlined?				
	Is the sample size large enough for sufficiently precise estimates?				
	Is the response rate large enough for sufficiently precise estimates?				
	Is the choice of population bias-free?				
	If a comparative study: Were participants randomized into groups? Were the groups comparable at baseline? If groups were not comparable at baseline, was incomparability addressed by the authors in the analysis?				
	Was informed consent obtained?				
Section B: Data Collection	Are data collection methods clearly described?				
	If a face-to-face survey, were inter-observer and intra-observer bias reduced?				
	Is the data collection instrument validated?				
	If based on regularly collected statistics, are the statistics free from subjectivity?				
	Does the study measure the outcome at a time appropriate for capturing the intervention's effect?				
	Is the instrument included in the publication?				
	Are questions posed clearly enough to be able to elicit precise answers?				
	Were those involved in data collection not involved in delivering a service to the target population?				
Section C: Study Design	Is the study type / methodology utilized appropriate?				
	Is there face validity?				
	Is the research methodology clearly stated at a level of detail that would allow its replication?				
	Was ethics approval obtained?				
	Are the outcomes clearly stated and discussed in relation to the data collection?				
Section D: Results	Are all the results clearly outlined?				
	Are confounding variables accounted for?				
	Do the conclusions accurately reflect the analysis?				
	Is subset analysis a minor, rather than a major, focus of the article?				
	Are suggestions provided for further areas to research?				
	Is there external validity?				
Calculation for section validity: (Y+N+U=T) If Y/T < 75% or if N+U/T > 25% then you can safely conclude that the section identifies significant omissions and that the study's validity is questionable. It is important to look at the overall validity as well as section validity.		Calculation for overall validity: (Y+N+U=T) If Y/T ≥ 75% or if N+U/T ≤ 25% then you can safely conclude that the study is valid.			
Section A validity calculation: Section B validity calculation: Section C validity calculation: Section D validity calculation:		Overall validity calculation:			

EBLIP Critical Appraisal Checklist
 Lindsay Glynn, MLIS
 Memorial University of Newfoundland
lglynn@mun.ca

Table 1.2. Results of the quality assessment

Study	Population %	Data collection %	Study design %	Results %	Overall score %	Quality rating
Coon et al. (2004)	66	33	80	100	66	Moderate
Haley et al. (2004)	50	50	80	83	66	Moderate
Heo & Koeske (2011)	50	20	60	66	49	Moderate
Hodge & Sun (2012)	50	33	80	66	58	Moderate
Kosberg et al. (2007)	50	50	80	66	62	Moderate
Lee et al. (2010)	50	50	80	83	67	Moderate
Mausbach et al. (2003)	50	33	60	83	57	Moderate
Morano & King (2005)	33	17	60	33	36	Low
Roff et al. (2004)	50	66	66	66	62	Moderate
Skarupski et al. (2009)	66	66	80	83	74	High
Sorensen & Pinquart, (2005)	50	33	66	66	54	Moderate
Spurlock et al. (2005)	66	60	80	50	56	Moderate
Sun & Hodge (2014)	66	17	60	50	48	Moderate
Sun et al. (2010)	66	60	80	83	72	High
Thompson et al. (2002)	50	50	50	50	66	Moderate

Appendix D

Author instructions for *Clinical Psychology and Psychotherapy*

Clinical Psychology & Psychotherapy

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Edited By: Paul Emmelkamp and Mick Power

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ISI Journal Citation Reports © Ranking: 2012: 36/114 (Psychology Clinical)

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Reviews: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

Assessments: Articles reporting useful information and data about new or existing measures.

Practitioner Reports: Shorter articles that typically contain interesting clinical material.

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Reference style . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

A. A typical citation of an entire work consists of the author's name and the year of publication .

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

B. If the author is named in the text, only the year is cited .

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .

Example: In a 1989 article, Gould explains Darwin's most successful. . .

D. Specific citations of pages or chapters follow the year .

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

E. When the reference is to a work by two authors, cite both names each time the reference appears .

Example: Sexual-selection theory often has been used to explore patters of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others") .

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the reference is to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

G. When the reference is to a work by a corporate author, use the name of the organization as the author .

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows .

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

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Book

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

Book with More than One Author

Natarajan, R., & Chaturvedi, R. (1983). *Geology of the Indian Ocean*. Hartford, CT: University of Hartford Press.
 Heslen, J., Carpenter, K., Moriber, H., & Milsop, A. (1983). *Computers in the business world*. Hartford, CT: Capital Press. and so on.
 The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.

Web Document on University Program or Department Web Site

Degelman, D., & Harris, M. L. (2000). *APA style essentials*. Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website: http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796

Stand-alone Web Document (no date)

Nielsen, M. E. (n.d.). *Notable people in psychology of religion*. Retrieved August 3, 2001, from <http://www.psywww.com/psyrelig/psyrelpr.htm>

Journal Article from Database

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence*, 15 , 503-522. Retrieved May 20, 2000, from ProQuest database.

Abstract from Secondary Database

Garrity, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology*, 20 , 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

Article or Chapter in an Edited Book

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Appendix E

Ethical Approval from Coventry University: Stage 1

Ethics Request Updated - Tanagh Williams

Page 1 of 1

Ethics Request Updated

CU Ethics <omis@coventry.ac.uk>

Tue 12/11/2013 17:32

To: Tanagh Williams <willi481@coventry.ac.uk>;



The following ethics request has been set a status of approved with minor conditions by Elaine Cartmill. All the relevant documentation will be available for you to download within the next 24 hours. Please log back into Ethics and select the request from your listing. Select the Downloads tab to retrieve the documentation.

Please proceed with good ethics.

Ref:	P16851
Project Title:	Trainee clinical psychologists' experiences of working with older people
Applicant:	Tanagh Williams
Supervisor:	Tom Patterson
Module Code:	D44PY
Module Leader:	

Go to ethics.coventry.ac.uk to view this request in more detail.

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15/03/2014

Appendix F

Ethical
Approval
from
Coventry
Universit
y: Stage
2

Ethics Request Updated - Tanagh Williams

Page 1 of 1

Ethics Request Updated

CU Ethics <omis@coventry.ac.uk>

Mon 09/12/2013 09:51

To: Tanagh Williams <willi481@coventry.ac.uk>;



The following ethics request has been approved by Joanna Hemming. All the relevant documentation will be available for you to download within the next 24 hours. Please log back into Ethics and select the request from your listing. Select the Downloads tab to retrieve the documentation.

Please proceed with good ethics.

Ref:	P19309
Project Title:	Trainee clinical psychologists' experiences of working with older people
Applicant:	Tanagh Williams
Supervisor:	Tom Patterson
Module Code:	D44PY
Module Leader:	

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15/03/2014

Appendix G

Email from local NHS Research and Development Team

RE: Clinical psychology doctoral study - Tanagh Williams

Page 1 of 3

RE: Clinical psychology doctoral study

Lapper Shelley (RKB) Project Support Officer <Shelley.Lapper@uhcw.nhs.uk> on behalf of Embury Natassia (RKB) RM&G Facilitator <Natassia.Embury@uhcw.nhs.uk>

Thu 24/10/2013 16:10

To: Tanagh Williams <willi481@uni.coventry.ac.uk>;

Dear Tanagh

As previously discussed you confirmed that your study will have no NHS Organisations or patient identifiable data, you will be requesting participants through the University via the course administrator using the course administration details and you will be interviewing the participants either at the University or at a place of their convenience. With this in mind, I can confirm that this study will not require NHS R&D Approval, and approval should be sought through your university.

Thank you

Shelley Lapper
R&D CSP Facilitator
West Midlands (South) CLRN

Please note my working hours are Monday - Thursday 9am - 4.30pm and Friday 9am-2pm

Tel.: 024 7696 4942 (ext: 24942)
Email.: shelley.lapper@uhcw.nhs.uk
General Enquires: rgadvice@uhcw.nhs.uk
CSP Central Inbox: uhc-tr.wmsclm@nhs.net

PA to the CLRN: Nicky Mortimer 024 7696 5031

Postal Address: CLRN Office, 4th Floor Rotunda, University Hospital Coventry and Warwickshire NHS Trust, Clifford Bridge Road, Coventry, CV2 2DX

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15/03/2014

Appendix H

Focus Group Invitation Email

FW: Third year research project - Tanagh Williams

Page 1 of 2

FW: Third year research project

Catherine Ashton <hsx982@coventry.ac.uk>

Wed 13/11/2013 09:47

Confidential Information (email addresses) removed

2 attachments

Participant Information Sheet 11.11.13.docx; Consent form 18.09.13.docx;

On behalf of Tanagh Williams:

Dear Trainee

RE: Invitation to participate in a research project

TITLE: "Trainee clinical psychologists' experiences of working with older people"

I am a third year trainee clinical psychologist on the Coventry and Warwick Clinical Psychology Doctorate.

I would like to invite you to take part in the above study.

This will involve phase 1 of the study: a focus group with the researcher and three other trainees to explore your experiences of working with older people. The focus group recording will be transcribed and used to devise the interview schedule for phase 2 of the study: individual semi-structured interviews. You will not be asked to take part in phase 2.

Please take your time to read the attached participant information sheet and consent form and decide whether you would like to take part.

If you have any questions or would like to take part, please do not hesitate to contact me at willi481@uni.coventry.ac.uk.

Many thanks for taking the time to read this email.

Kind regards

Tanagh

Tanagh Williams
Trainee Clinical Psychologist
Universities of Coventry and Warwick Clinical Psychology Doctorate

<https://pod51036.outlook.com/owa/>

19/06/2014

Appendix I

Focus Group Participant Information Sheet

Participant Information Sheet

“Trainee clinical psychologists’ experiences of working with older people”

A study by Tanagh Williams, Tom Patterson and Jane Muers at Coventry University
Clinical Psychology Doctorate

We would like to invite you to take part in a research study. Before you decide whether to take part it is important for you to understand why we are doing the research and what it will involve. Talk to others about it if you wish. Please do not hesitate to contact the researcher, or one of her supervisors, if anything is unclear or if you have any further questions.

What is the purpose of the study?

The aim of the study is to explore trainee clinical psychologists’ experiences of working with older people during training. The research study has been designed to focus on a current gap in the research literature and will aim to extend the literature base in this area.

Why have I been invited to take part?

The researcher is contacting trainee clinical psychologists and recently qualified (in 2013) clinical psychologists from West Midlands’ clinical psychology training courses. In order to take part in the study, trainees must have completed at least 12 weeks of a placement where 50-100% of direct client work was with older people (aged 65 and above). This is in order to ensure that participants have had sufficient experience of working with older people during training before they participate.

Do I have to take part?

It is your choice whether to take part or not. If you decide to take part you will be asked to sign a consent form to indicate that you have read and understood this participant information sheet and agree to take part in the study. You can still change your mind and withdraw from the study at any time, within one month from the date the consent form is signed.

What will happen if I agree to take part?

Phase 1 of the study involves participating in a focus group of four people (all from Year 3 Coventry/Warwick clinical psychology doctorate), as well as the researcher. You will be asked to discuss your experiences of working with older people during training. If you would like to take part, you can contact me via email or leave a telephone message with the clinical psychology office (details below). You will then be contacted to arrange a mutually convenient interview date, time and venue.

The focus group will last approximately 30-40 minutes and will be voice recorded for the purpose of data analysis and transcribed. Before the recording begins you will have an opportunity to ask questions about the study and be asked to sign the consent form. The focus group comprises phase 1 of the research study, and it will be used to devise interview questions for phase 2 of the study: individual semi-structured interviews. You will not be asked to participate in phase 2 of the study.

What are the possible risks or benefits of taking part?

The research is about your experiences and you will be asked to say as much as you feel comfortable with. It is possible that talking about your experiences may evoke some emotional distress. Should this happen I will have copies of the West Midlands Therapy Network Register available for you to take away or you can contact your GP. If you do find it difficult to answer the questions please remember that we can stop the interview at any time. I am not able to offer participants any direct rewards for taking part in the study.

Will my information be kept confidential?

Participants in the focus group will be asked to respect each other's confidentiality and anonymity. The focus group recording will be transferred onto a password protected file on the researcher's personal computer and the recording will then be deleted from the digital audio recording device. The recording will be transcribed by the researcher and anonymised in a password protected file. A paper copy of the anonymous transcript will be used for analysis by the researcher, which may be viewed by her supervisors and other members of the clinical psychology team. Following study completion, your information will be stored securely by Coventry University for five years before being destroyed, in line with British Psychological Society (BPS) guidelines. Study findings, including anonymous quotes and

extracts, may be included in the final paper, for the doctoral thesis submission and any further dissemination, such as journal articles and conference presentations.

What if there is a problem? If you are concerned about any aspect of this study, please contact the researcher or one of her supervisors (see contact details below).

What will happen to the results of this study? The results of this study may be put forward for publication in psychology and/or mental health journals. If you would like to receive a summary of the findings please contact the researcher (see contact details below).

Thank you for taking time to read this information.

Researcher:

Tanagh Williams, Trainee Clinical Psychologist. Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: willi481@uni.coventry.ac.uk

Clinical Supervisor:

Jane Muers, Clinical Psychologist. Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328

Academic Supervisor:

Dr Tom Patterson, Clinical Psychologist. Academic Director - Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328

Appendix J

Focus Group Consent Form

Participant Consent Form

Study Title: "Trainee clinical psychologists' experiences of working with older people"

Please initial box

1. I confirm that I have read and understood the information sheet dated 18/09/2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I can withdraw at any time during the interview and within one month from today's date without giving a reason.

3. I consent to this focus group being audio recorded and I understand that it will be deleted from the digital audio recorder once it has been transferred to the researcher's personal computer in a password protected file.

4. I understand that the focus group recording will be transcribed and anonymised and a copy will be used by the researcher to complete the thematic analysis, which may also be seen by her supervisors.

5. I understand that findings from the thematic analysis will be used by the researcher to devise interview questions for the study and that my anonymised quotes/ extracts may be included in the final paper, comprising the doctoral thesis submission and any further dissemination.

6. I understand that I can contact the researcher if I have any questions or concerns.

7. I agree to take part in the above study.

Participants Name

Date

Signature

Researchers Name

Date

Signature

Please tick this box if you would like to receive a summary of the findings by email ☐

Preferred email address.....

Appendix K

Focus Group Interview Schedule

I am interested in trainees' experiences of working with older people. I want to hear about your personal experiences. Please give as much detail as you can, as long as you feel comfortable. Please also respect each other's confidentiality and anonymity and ensure that information discussed today is not shared with anyone else.

Let me know if any of you need take a break at any point. As you know, I am recording the focus group, so please do tell me if you want me to stop the recording at any time. I'm interested in all of your own experiences whatever these may be.

Question 1

Could you tell me about your experience(s) of working with older people both prior to commencing clinical training and during clinical training?

Question 2

Looking back over your placement experience, can you comment on the interactions you had with older clients / service users?

Question 3

Can you tell me about what it was like to work clinically with older people?

Question 4

What other factors were relevant to how you experienced this work?

Appendix L

Thematic Analysis of Focus Group Transcript

Main themes	Subthemes
Differences between working with older people and other areas	Less understanding of psychological ideas/ talking about feelings
	Longer history, poignancy of going further back
	Wide variety of work
Dementia diagnosis process	Adapting to contexts in which assessments took place
	Challenges of giving feedback
	Facilitating psychological adjustment to life changing diagnosis
Relationships with older people and their carers / family	Boundaries blurred
	Resistance
	Finding common ground
Enjoyable aspects of the work	Group work
	Informality, social aspect
	Dementia work
What is brought to therapy	Multiple losses
	Changes to home life / environment
	Precipitated by loss of physical abilities / previous coping strategies
How I feel as the therapist	Want to help versus can't help
	Diagnostic process as overwhelming
	Reminders of older people and losses in own life
	Frustrations about unsuitable working environments

Appendix M

Interview Schedule for Interviews

Interview Schedule

Opening question:

Can you tell me about your placement(s) where you worked with older people?

- Service
- Location

Questions to be covered (with suggested prompts if the participant is having difficulty answering the question):

1. Can you say a little about your experience of working with older clients on placement?
2. What knowledge, skills or experience did you draw upon or find helpful in your therapeutic -work with older people?
 - E.g. Psychological Theories; Therapeutic models or modalities; Personal experience
3. Can you tell me about your experience of conducting cognitive assessments, including giving feedback to clients (if this formed a part of your role)?
4. Were there aspects of the work that you enjoyed or that you found particularly difficult?
 - Any examples? (e.g. particular interactions you remember liking or finding difficult or feelings evoked by working with certain clients)
5. Did your clinical work with older clients have a personal impact on you?
 - In what ways?
 - (If yes), how did you manage any personal impact while you were on placement?
6. If your placement experience included work with families or carers could you tell me about what that was like?

7. Was your experience of working clinically with older people similar to or different from your experience of working with other groups?
 - In what ways?

Potential follow up questions / additional prompts:

- You said X, can you give me an example of that / can you say a bit more about that?
- I'd be interested to hear a little more of your thoughts about that.
- What was it like?

Appendix N

Demographic Questionnaire

Demographic Questionnaire

Study Title: “Trainee clinical psychologists’ experiences of working with older people”

1. Your name:.....

2. Your gender: (please circle) Male Female

3. Your age (in years):.....

4. Which ethnic group do you belong to?

Please indicate by ticking the relevant box:

White	British	
	Irish	
	Other White	
Mixed	White and Black Caribbean	
	White and Black African	
	White and Asian	
	Other Mixed	
Asian or Asian British	Indian	
	Pakistani	
	Bangladeshi	
	Other Asian	
Black or Black British	Caribbean	
	African	
	Other Black	

Chinese or other ethnic group	Chinese	
	Other ethnic group (please specify)	

5. What is your current stage of training? (Please circle)

Year 1 / 2 / 3 / Recently qualified in 2013

6. What is the name of the Clinical Psychology Doctorate on which you are currently enrolled / from which you have recently qualified:

.....

7. Type of placement during training where at least 50% of direct client work was with older people (aged 65 and above). Please circle:

Older people's mental health Physical Health Neuropsychology

Other (please state)

8. Your experience of working with older people prior to clinical psychology training:

Role	Duration of post (in months)
.....
.....
.....

Thank you for taking the time to complete this questionnaire.

Appendix O

Gatekeeper permission from Coventry University

Re: Request for permission to invite trainees to particip... - Tanagh Williams

Page 1 of 2

Re: Request for permission to invite trainees to participate in a study

Eve Knight <hsx351@coventry.ac.uk>

Mon 09/12/2013 16:51

To: Tanagh Williams <willi481@uni.coventry.ac.uk>;

Hi Tannagh
Of course it is fine!
Good luck with it - please just liaise with Catherine about emailing out to trainees.
Regards
Eve

Sent from my iPhone

On 9 Dec 2013, at 14:58, "Tanagh Williams" <willi481@uni.coventry.ac.uk> wrote:

Dear Dr Eve Knight

I am writing to tell you about my clinical psychology doctoral project exploring 'Trainee clinical psychologists' experiences of working with older people' and to request your permission to recruit trainees from the Universities of Coventry and Warwick Clinical Psychology Doctorate to participate in the study.

The study has received ethical approval from Coventry University.

If you agree, I will send an invitation email to your course administrator to forward onto trainees.

I have attached the participant information sheet for further information. Please do not hesitate to contact me if you have any further questions.

Many thanks for taking the time to read this email.

Kind regards

Tanagh Williams
Trainee Clinical Psychologist
Universities of Coventry and Warwick Clinical Psychology Doctorate
willi481@uni.coventry.ac.uk
Tel. 02476 888328

<Participant Information Sheet 09.12.13.docx>

<https://pod51036.outlook.com/owa/>

21/04/2014

Appendix P

Gatekeeper permission from Birmingham University

Re: Request for permission to invite trainees to particip... - Tanagh Williams

Page 1 of 2

Re: Request for permission to invite trainees to participate in a study

Theresa Powell <t.powell@bham.ac.uk>

Mon 09/12/2013 20:16

To: Tanagh Williams <willi481@uni.coventry.ac.uk>;

Cc: Ann Begum <A.A.BEGUM@bham.ac.uk>;

Thats fine Tanagh, Anne will send out an email for you but please note we can't give you any email addresses directly.

Good luck

BW

Theresa

Theresa Powell PhD, C.Psychol, AFBPsS
Programme Director
Doctorate in Clinical Psychology
School of Psychology
University of Birmingham
Edgbaston
Birmingham B15 2TT
Tel (+44) 0121 414 7124
t.powell@bham.ac.uk <<mailto:t.powell@bham.ac.uk>>

On 9 Dec 2013, at 17:15, "Tanagh Williams" <willi481@uni.coventry.ac.uk <<mailto:willi481@uni.coventry.ac.uk>>> wrote:

Dear Dr Theresa Powell

As part of the email below, I am also requesting permission to invite those who recently qualified from the course in 2013 via your course administrator.

I look forward to hearing from you.

Many thanks

<https://pod51036.outlook.com/owa/>

21/04/2014

Appendix Q

Invitation Email to Coventry University

Invitation to participate in a research project - Tanagh Williams

Page 1 of 2

Invitation to participate in a research project

Tanagh Williams

Mon 09/12/2013 17:11

To: Catherine Ashton <hsx982@coventry.ac.uk>;

📎 1 attachment

Participant Information Sheet 09.12.13.docx;

Hi Catherine, please could you forward the email below + attachment to all second year trainees and all those who qualified from the course in Sept 2013?
Have just got agreement from Eve.
Many thanks!
Tanagh

Dear Trainee

RE: Invitation to participate in a research project

TITLE: "Trainee clinical psychologists' experiences of working with older people"

I am a third year trainee clinical psychologist on the Coventry and Warwick Clinical Psychology Doctorate.

I would like to invite you to take part in the above study. Please take as much time as you need to consider whether you would like to take part.

The study will involve a semi-structured interview to find out more about your personal experiences, at a location which is convenient for you.

As the main researcher on the project, I will be interviewing all participants. The interview will last approximately one hour but this will be flexible and no longer than 90 minutes.

Participants will need to have completed at least 12 weeks of one training placement (older adult, neuropsychology, physical health or other) where 50-100% of direct clinical work was with older people (aged 65 or above). I am looking for people who completed this placement no longer than 18 months ago.

If you have any questions or would like to take part, please do not hesitate to contact me at willi481@uni.coventry.ac.uk or you can telephone the Clinical Psychology office on 024 7688 8328 and leave a message for me to call you back.

Many thanks for taking the time to read this email.

<https://pod51036.outlook.com/owa/>

17/06/2014

Appendix R

Invitation Email to Birmingham University

Invitation to participate in a clinical psychology resear... - Tanagh Williams

Page 1 of 2

Invitation to participate in a clinical psychology research project

Tanagh Williams

Tue 10/12/2013 13:23

To: Ann Begum <A.A.BEGUM@bham.ac.uk>;

📎 1 attachment

Participant Information Sheet 09.12.13.docx

Dear Ann

Following permission from Dr Theresa Powell, please could you forward the invitation email below + attachment to all of your second and third year trainees as well as those who recently qualified from the course in 2013.

Many thanks

Tanagh Williams
Trainee Clinical Psychologist
Universities of Coventry and Warwick Clinical Psychology Doctorate

Dear All

RE: Invitation to participate in a research project

TITLE: "Trainee clinical psychologists' experiences of working with older people"

I am a third year trainee clinical psychologist on the Coventry and Warwick Clinical Psychology Doctorate.

I would like to invite you to take part in the above study. Please take as much time as you need to consider whether you would like to take part.

The study will involve a semi-structured interview to find out more about your personal experiences, at a location which is convenient for you.

As the main researcher on the project, I will be interviewing all participants. The interview will last approximately one hour but this will be flexible and no longer than 90 minutes.

Participants will need to have completed at least 12 weeks of one training placement (older adult, neuropsychology, physical health or other) where 50-100% of direct clinical work was with older people (aged 65 or above). I am looking for people who completed this placement no longer than 18 months ago, whether you are a current trainee or recently qualified from the course in 2013.

If you have any questions or would like to take part, please do not hesitate to contact me at will481@uni.coventry.ac.uk or you can telephone the Clinical Psychology office on 024 7688 8328 and leave a message for me to call you back.

<https://pod51036.outlook.com/owa/>

17/06/2014

Appendix S

Participant Information Sheet for Interviews

Participant Information Sheet

“Trainee clinical psychologists’ experiences of working with older people”

A study by Tanagh Williams, Tom Patterson and Jane Muers at Coventry University

Clinical Psychology Doctorate

We would like to invite you to take part in a research study. Before you decide whether to take part it is important for you to understand why we are doing the research and what it will involve. Talk to others about it if you wish. Please do not hesitate to contact the researcher, or one of her supervisors, if anything is unclear or if you have any further questions.

What is the purpose of the study?

The aim of the study is to explore trainee clinical psychologists’ experiences of working with older people during training. The research study has been designed to focus on a current gap in the research literature and will aim to extend the literature base in this area.

Why have I been invited to take part?

The researcher is contacting trainee clinical psychologists and recently qualified (in 2013) clinical psychologists from West Midlands’ clinical psychology training courses. In order to take part in the study, trainees must have completed at least 12 weeks of a placement where 50-100% of direct client work was with older people (aged 65 and above). This is in order to ensure that participants have had sufficient experience of working with older people during training before they participate. Participants will also need to have completed this placement within the last 18 months to ensure that they can remember their experiences.

Do I have to take part?

It is your choice whether to take part or not. If you decide to take part you will be asked to sign a consent form to indicate that you have read and understood this participant information sheet and agree to take part in the study. You can still change your mind and withdraw from the study at any time, within one month from the date the consent form is signed.

What will happen if I agree to take part?

The study involves participating in an interview where you will be asked questions about your own experiences of working with older people on placement. If you would like to take part, you can contact me via email or leave a telephone message with the clinical psychology office (details below). You will then be contacted to arrange an interview date, time and venue which are convenient for you.

The interview will last approximately one hour. However, this will be flexible according to each individual and will last no longer than 90 minutes. The interview will be voice recorded for the purpose of data analysis and later transcribed. However, before the recording begins you will have an opportunity to ask questions about the study and be asked to sign the consent form.

What are the possible risks or benefits of taking part?

The research is about your experiences and you will be asked to say as much as you feel comfortable with. It is possible that talking about your experiences may evoke some emotional distress. Should this happen I will have copies of the West Midlands Therapy Network Register available for you to take away or you can contact your GP. If you do find it difficult to answer the questions please remember that we can stop the interview at any time. I am not able to offer participants any direct rewards for taking part in the study.

Will my information be kept confidential?

The interview recording will be transferred onto a password protected file on the researcher's personal computer and the recording will then be deleted from the digital audio recording device. The interview recording will be transcribed by the researcher and anonymised in a password protected file. A paper copy of the anonymous transcript will be used for analysis by the researcher, which may be viewed by her supervisors and other members of the clinical psychology team for validation. Following study completion, your information will be stored securely by Coventry University for five years before being destroyed, in line with British Psychological Society (BPS) guidelines. Study findings, including anonymous quotes and extracts, may be included in the final paper, for the doctoral thesis submission and any further dissemination, such as journal articles and conference presentations.

What if there is a problem? If you are concerned about any aspect of this study, please contact the researcher or one of her supervisors (see contact details below).

What will happen to the results of this study? The results of this study may be put forward for publication in psychology and/or mental health journals. If you would like to receive a summary of the findings please contact the researcher (see contact details below).

Thank you for taking time to read this information.

Researcher:

Tanagh Williams, Trainee Clinical Psychologist. Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: willi481@uni.coventry.ac.uk

Clinical Supervisor:

Jane Muers, Clinical Psychologist. Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328

Academic Supervisor:

Dr Tom Patterson, Clinical Psychologist. Academic Director - Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328

Appendix T

Consent Form for Interviews

Version 2: 21.10.13

Participant Consent Form

Study Title: "Trainee clinical psychologists' experiences of working with older people"

Please initial box

1. I confirm that I have read and understood the information sheet dated 21/10/2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I can withdraw my information at any time without giving a reason within one month from today's date.

3. I consent to my interview being audio recorded and I understand that it will be transferred from the digital audio recorder to the researcher's personal computer in a password protected file.

4. I understand that the interview will be transcribed verbatim, anonymised with a unique identifier, and stored on the researcher's computer in a password protected file.

5. I understand that findings from the study, including anonymised quotes/ extracts from the recording, may be included in the final paper, comprising the doctoral thesis submission and any further dissemination, such as journal articles and conference presentations.

6. I agree to take part in the above study.

_____ Participants Name	_____ Date	_____ Signature
_____ Researchers Name	_____ Date	_____ Signature

Please tick this box if you would like to receive a summary of the findings ☐

Preferred email address.....

<p>others highlighting positives</p> <p>Compassion for clients</p> <p>Enjoyment and value from the emotional work.</p> <p>Markedly</p> <p>Reminders of own family.</p>	<p>363 kind of <u>bad news</u> actually quite thankful of the</p> <p>364 recommendations and the support that could come with</p> <p>365 that, um.. So even though it was in...maybe the outcome</p> <p>366 was negative it..I was surprised that people found it,</p> <p>367 most..yeah people I worked with found it quite positive if</p> <p>368 that makes sense? Yeah.</p> <p>369 I: Yeah, yeah.</p> <p>370 R: I suppose I <u>guess</u> it means for the family certainly,</p> <p>371 there.. it's been recognised that there's these difficulties</p> <p>372 going on and actually I guess it's a <u>step forward</u> to..yeah,</p> <p>373 getting some help.</p> <p>374 I: Hmm, great. And um, were there aspects of the work</p> <p>375 that you particularly enjoyed or you found particularly</p> <p>376 difficult?</p> <p>377 R: Um (pause), I think I enjoyed pretty much all of it, I</p> <p>378 think the bits I <u>enjoyed</u> the most were the <u>group work</u></p> <p>379 definitely with the carers and um those living with</p> <p>380 dementia and I think but at the same time that was um,</p> <p>381 yeah sometimes the hardest bit and I think giving kind of</p> <p>382 feedback um, whilst I know that people felt it was</p> <p>383 positive I don't know, just something really sad about</p> <p>384 kind of... Yeah giving news that someone's got dementia,</p> <p>385 even if you're just writing it in the report, there's</p> <p>386 something, I don't know.</p> <p>387 I: There's something about giving that news.</p> <p>388 R: Yeah it's quite I think because you I guess you know,</p> <p>389 you've got an idea of how things might <u>deteriorate</u> and it</p> <p>390 just..you can kind of I guess we..sometimes we see worst</p> <p>391 case scenarios I guess and I don't know, it's just I think it's</p> <p>392 just quite, quite sad so I think that's probably the most</p> <p>393 difficult um..and I guess it kind of makes you think about</p> <p>394 your own grandparents or parents even, kind of yeah</p> <p>395 how would that, yeah that feel of that...I don't know</p>	<p><u>feedbacks back bad news</u> support helped</p> <p>↓ even if dementia.</p> <p><u>positive process</u>.</p> <p>rhetorical question or question to me? unsure if makes sense for dementia assessment to be positive? I guess - some daisy still? → Can see how will help family.</p> <p>→ step forward suggests movement. important as a progress trainee to see that?? - want them to get support</p> <p>group work - enjoyed most.</p> <p>dementia hardest at same time - feedback particularly.</p> <p>sad giving news.</p> <p>→ I don't know → means hard to articulate?</p> <p>deteriorate.</p> <p>worst case scenarios.</p> <p>sad, more difficult making link sad to own family.</p> <p>own grandparents or parents.</p> <p>imagining self in their shoes - person in dementia or carer.</p>
--	--	--

Andy

Example of the data analysis

Appendix U

<i>coincidents parents future discriminate indiscriminate (dementia) not in my control</i>	<p>396 there was that kind of personal side as well, I mean I 397 don't have anyone in my family with dementia but I've 398 got kind of older, older parents who you kind of think 399 gosh, you know, it happens to anyone, you know any 400 family, yeah kind of think, you think about those sorts of 401 things. 402 I: Hmm, yeah there was something I was going to kind 403 of ask about in what ways did, or did the clinical work 404 have a personal impact on you? 405 R: I think it just, I don't know old age is something that's 406 going to happen to us all and I think I don't know it's not 407 something we, well not something I've, I don't like to 408 think about, I don't really like to think about the end bit 409 do you? (Laughter) 410 R: Um, and I think kind of doing, working with older 411 adults kind of, it brings that very much to the, to the fore 412 and I think um, you know touching wood <u>all my family</u> 413 <u>are quite well</u> at the moment and things, but I think it 414 just, it just makes you think actually, you know my 415 parents aren't getting any younger and you know, the 416 relatives are..I don't know kind of yeah, are getting on a 417 bit, yeah I think it does kind of, I <u>guess brings it more into</u> 418 <u>your mind</u>, um and..I don't know and kind of, I don't 419 know makes you see....I guess because you're seeing 420 older adults that are kind of in some ways more 421 <u>vulnerable</u> and even though they are <u>resilient</u> they're 422 really <u>struggling</u> with changes in health and you know 423 kind of talking to them, I think you always, I always felt, 424 you know I'm not young, young, but I always felt like the 425 younger, <u>(like they could be my grandparent)</u> I suppose, I 426 think that in itself kind of brings a, an odd, an odd feeling, 427 um.. 428 I: So you say you being younger brings an odd feeling?</p>	<p>no one in our family with dementia. older parents - closer to it? <u>to anyone</u> → it could happen to me. gosh - suggest surprise? realisation? suggests as a society. happen to us all → then I don't like <u>we not I distancing?</u> → language to distance rather than death? rhetorical of. <u>brings to the fore</u>. (touching wood) superstition (expression) just makes you think realisation. placement makes you think about it more. <u>future</u>. vulnerability of clients + resilience holding both of these in mind. not really young 'the younger' - compare could be my grandparent. set the odd feeling. link to family older person</p>
---	---	--

429 R: Yeah I'm not sure I articulated that right. Kind of, I
 430 guess a lot of..you know a lot of the older adults, maybe
 431 couldn't have been my grandparents, but yeah kind of
 432 older, that older figure that I kind of, you think of as a
 433 grandparent and I think that's quite a, I don't know it's
 434 quite a strange...because you're going in as the
 435 professional I don't know there's a certain kind of...I
 436 don't know how to describe it, I, kind of that weird, (long
 437 pause) um.
 438 I: So you said there's something about being younger and
 439 then also being the professional.
 440 R: Yeah it's a bit of a conflict and I think as a trainee as
 441 well certainly on kind of first placement you, you feel,
 442 you don't feel as, maybe as confident as, as you might do,
 443 um and kind of then working with, with older adults who,
 444 I don't know, you don't really want, not that you tell any
 445 client that they're wrong, but, kind of when working with
 446 them...I don't know it brings a different sort of respect, or
 447 kind of, you know respecting your elders.
 448 I: Yeah.
 449 R: Um I don't know just a different feeling of yeah when
 450 you're working with them, I'm not sure I can articulate it.
 451 I: Just earlier you said vulnerable what did you mean
 452 when you said that?
 453 R: I think there's something about vulnerability in
 454 particular with regards to kind of failing physical health
 455 I: OK
 456 R: The changes that have gone on with that and I think
 457 just how isolated as well, even with kind of families, you
 458 know, very strong families around them I think certainly
 459 with some of the clients I worked with kind of...certainly
 460 the men, the kind of stiff upper lip, kind of very British
 461 kind of that older generation where I guess kind of

Noticing
the age
difference

sense of
authority
limited

understanding
their perspective

vulnerability
of clients

unexpressed
feelings of
clients

wanting to make sense.

awareness of difference
older figure - makes think of own grandparents
strange, the professional
pauses - suggest hard to articulate

conflict:
- what's 1st placement/what's older adult
work is particularly
feel less confident around
older people?

wrong - not want to challenge?
difficult to challenge?

a different feeling.
→ hard to articulate

failing physical health.

isolated within families → families don't
reduce isolation
trainee - as wanting to reduce
shows families - importance of work -
stiff upper lip - suggests not telling about
feelings.

Appendix V

Emergent themes for one participant

Andy (pseudonym)		
Superordinate themes	Subordinate themes	Examples
Sharing stories <i>"They've got lots of stories" (L37)</i>	Power of a group <i>"I think just the power of a group" (L536)</i>	<i>"the humour they come with" (L200), "it felt an honour actually" (L201), "the support they gave each other" (L540), "really, really valuable" (L638), "speak to someone who really gets that" (L656)</i>
	Humanness <i>"I'm human it's alright" (L480)</i>	<i>"heartbreaking" (L192) "together...so many years" (L193) "the emotional impact on you" (L485), "it's human to feel that" (L490)</i>
	Importance of feedback <i>"the feedback, how important that is" (L566)</i>	<i>"clients were...genuinely quite thankful" (L354), "people I worked with found it quite positive" (L267), "they seemed to find it valuable" (L361), "to be able to get carers' perspective" (L557)</i>
	Time and space <i>"giving people time and space" (L221)</i>	<i>"giving them the time" (L95), "being with someone, that's what was really valued" (L226), "value of core listening skills" (L225)</i>
Importance of compassion and acceptance <i>"Compassion focused" (L150)</i> <i>"Acceptance" (L163)</i>	Noticing resilience <i>"their resilience is amazing" (L146)</i>	<i>"so many resources already" (L133), "they'd got that far" (L141), "building on their resources" (L178)</i>
	Recognising what you can't change <i>"you can't change any of those things for the client" (L166)</i>	<i>"there is no cure for it" (L118), "learning to live with that in a different way" (L170), "they didn't want to learn new skills, like do you know what I mean?" (L232), "that normal's going to be different now" (L262)</i>
	Unexpressed feelings <i>"not being able to express" (L293)</i>	<i>"can't allow themselves to express themselves" (L467), "stiff upper lip to their families" (L469) "when given the opportunity there's a lot of feelings and emotions there" (L465)</i>

<p>Mortality as universal</p> <p>"going to happen to us all" (L406)</p>	<p>Increased awareness of mortality</p> <p>"discussions with people about death" (L739)</p>	<p>"you've got an idea of how things might deteriorate" (L389), "the scary what will the future look like" (L627), "open...about death" (L713), "there's not as much looking forward" (L710), "might drop dead tomorrow...real prospect" (L728), "not conversations I've really ever had...with other client groups" (L749)</p>
	<p>Personal link</p> <p>"just makes you think...my parents aren't getting any younger" (L414)</p>	<p>"makes you think about your own grandparents or parents even" (L393), "it happens to anyone" (L399), "touching wood all my family are quite well at the moment" (L412), "you're own mortality...friends and family's...mortality" (L735)</p>
	<p>Death as a difficult subject</p> <p>"it's quite a difficult subject to talk about" (L742)</p>	<p>"it's not something we....I don't really like to think about the end bit" (L407), "I find that quite uncomfortable" (L731), "so I think that makes the work harder" (L747)</p>
<p>Negotiating the professional role</p> <p>"you're going in as the professional" (L434)</p>	<p>Getting the balance right</p> <p>"finding that balance" (78)</p>	<p>"doing them therapeutically, yet...read the script" (L79), "big responsibility to get that right" (L119), "sift out what belonged to what" (L687), "realistically...what could I help him with" (L691), "what's beneficial" (L705)</p>
	<p>Seeing the value</p> <p>"I really, really valued it"</p>	<p>"seeing them used in that way made them feel a lot more valuable" (L340), "being able to give them some support" (L610), "really useful and really important" (L532), "really making them useful" (L335)</p>
	<p>Position in relation to the older client</p>	<p>"I'm not young, young, but I always felt like the younger" (L424), "an odd feeling" (L426), "that older figure" (L432), "respecting your elders" (L447), "I'm no nurse or doctor" (L677)</p>
	<p>Becoming more comfortable in dementia assessment role</p> <p>"didn't sit comfortably with me" (L76)</p>	<p>"it's something about giving someone that news" (L56) "it felt too concrete" (L74) "it felt really scary" (L109), "come to terms with doing assessments" (L563), "a tool...sat more comfortably with me" (L341)</p>