Investigating the Impact of Volunteer Mentoring on Carers of People with Dementia and Volunteer Mentors

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Abstract

Volunteer mentoring (befriending and peer support) is provided across a wide range of services for people with varying health conditions. Despite such services for carers of people with dementia increasing in number, there is little evidence for the benefits they may offer. Using a pragmatic approach, this thesis investigated the impact of volunteer mentoring on carers. It also explored the processes by which volunteer mentoring works and the experiences of volunteers delivering the interventions, many of whom are former carers.

A systematic review and survey of volunteer mentoring services highlighted conflicting findings surrounding the impact of the services, the perceived importance of experiential similarity of volunteers and matching carers and volunteers. However, reported outcomes from the systematic review and survey were more consistent, namely reducing emotional distress, loneliness and social isolation of carers. To explore these issues in greater depth, a sequential explanatory mixed methods design was adopted. Data were collected from carers using validated rating scales (HADS, MSPSS and the UCLA Loneliness Scale) and semi-structured interviews. Data collection from volunteers was by semi-structured interviews only. No statistically significant changes were found after the six month study period for anxiety, depression or loneliness for carers. However, significant differences in perceived social support scores were found ($p = 0.042$). Post-hoc analysis showed this to be between baseline and three months follow-up ($p = 0.015$). Of the three subscales of the MSPSS, only support from a ‘significant other’ was shown to be statistically significant between baseline and three months ($p = 0.013$). Qualitative findings showed volunteer mentoring to be an important source of emotional and social support for carers, which was facilitated by the volunteers’ experiential similarity. Similarly to carers, volunteers reported the importance of experiential similarity in developing bonds with carers. They discussed the importance of developing mutually beneficial relationships which leads to a two-way flow of support. Volunteers also reported satisfaction and enjoyment from their roles. Data integration showed volunteer mentoring can be a source of social support for carers. The statistically significant difference in perceived social support from a ‘significant other’ between baseline, three months follow up, was confirmed by carers taking part in the qualitative phase. They perceived that volunteer mentoring can help them be networked into other services and help them to cope better with their caring role.

It is argued that volunteer mentoring is an important source of support for some carers and that the development of these types of services should be considered alongside other forms of social support. This was one of the first studies of its kind to investigate both the process of volunteer mentoring and its impact specifically on carers of people with dementia. It is concluded that without experiential similarity, carers and volunteers may not develop the level of trust necessary to form mutually beneficial relationships.

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List of abbreviations

AD	Alzheimer's Disease
BME	Black and Minority Ethnic
BPSD	Behavioural and Psychological Symptoms of Dementia
DoH	Department of Health
GP	General Practitioner
HADS	Hospital and Anxiety Depression Scale
MCID	Minimum Clinically Important Difference
MSPSS	Multidimensional Scale of Perceived Social Support
ONS	Office for National Statistics
PICO	Patient, Intervention, Comparison and Outcome process
PRISMA	Preferred Reporting Outcomes for Systematic Reviews and Meta-Analyses
PWD	Person with Dementia
SAE	Stamped Addressed Envelope
SET	Social Exchange Theory
UCLA Loneliness Scale	University of California-Los Angeles Loneliness Scale
UK	United Kingdom

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Chapter One: Introduction

Carers (sometimes called family carers, informal carers or caregivers) of people with dementia often experience numerous difficulties in their caring role (Etters et al. 2008; Ory et al. 2000). They also have an increased risk of developing mental and physical health issues when compared to carers of people with other conditions and non-carers (Pinquart & Sörensen, 2007). Helping carers cope with difficulties and supporting them in the community is a priority not only for the governments of the countries of the United Kingdom (UK), but many high and medium income countries throughout the world (Alzheimer's Disease International (ADI), 2013). Increasingly, volunteers are delivering social support services (Naylor et al. 2013) and this raises a range of questions about the experiences, processes and impact of these types of services. Informed by my experience working in the voluntary sector supporting carers of people with dementia, this research explores the impact of volunteer mentoring on carers of people with dementia and the experiences of the volunteers who deliver the support. Volunteer mentoring was used in this research as an umbrella term which encompasses befriending, mentoring and peer support.

This introductory chapter provides an overview of the contextual background to the thesis, the research questions and aims, and maps out the chapters that follow. It sets out the evidence of the experiences of carers from international and English perspectives and English policy responses, with particular reference to volunteer services. Finally, this chapter documents the objectives and research questions of the thesis and gives an introduction to its overall structure.

1.1 Context of informal caring

1.1.1 Definitions

The focus of this research was on informal or family carers providing care to family members or friends in the community. A carer has been defined as someone who:

> "*...provide(s) unpaid care by looking after an ill, frail or disabled family member, friend or partner*" (Carers UK, 2009).

Unpaid informal carers are distinguished from paid formal carers. Whilst there can be a primary or main carer, dementia can have a far reaching impact within families, meaning there can also be secondary carers. These are likely to be adult children supporting a parent who is caring for the other parent (Gilliard, 2001). Formal care is often provided by:

> "*...care workers, nursing staff or other health and social care professionals. It can constitute personal care, helping the person with everyday tasks such as getting washed or dressed, or can consist of medical or nursing care.*" (Alzheimer's Society, 2014a)

Caring as provided by informal or family carers goes beyond the usual care provided by family members to each other and has been described as:

> "*...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting*" (Schultz & Martire, 2004).

Many people do not recognise themselves as carers, viewing the care they give as a normal part of family and relationship roles (Hughes et al. 2013). However, despite the ambiguity of the term 'carer', its use is important to bring people together who have similar issues in common and to keep carers' needs high on the social care agenda (Heron, 1998).

For the purpose of clarity throughout this thesis, primary informal or family carers are referred to as carers unless otherwise stated.

1.1.2 Informal caring

Worldwide, the number of carers generally is increasing as people live longer (Harwood et al. 2004). In England and Wales it was estimated that between 2001 and 2011 the number of carers increased by 600,000, from 5.2 million to 5.8 million (White, 2013). This figure is projected to continue rising to approximately nine million by 2037 (Carers UK, 2014a). Carers are essential to the UK economy, with the economic contribution estimated to be £119 billion per year, which is more than the total cost of the NHS at 98.8 billion per year (Buckner & Yeandle, 2011).

A survey of English households by the Health and Social Care Information Centre (HSCIC, 2010), reported that six in ten carers are female, the majority of them are White (92%) and most are aged between 45 and 64 years. However, a quarter of carers are aged 65 or over and this group provides more care than younger carers. There is also evidence to suggest that the number of older carers (aged 85 and over) is increasing, with analysis of the 2011 Office for National Statistics (ONS) census revealing a rise of 128% within a decade (Carers UK & Age UK, 2015). The majority of carers (six in ten) report being pushed to 'breaking point' by the difficulties they experience due to caring (Carers UK, 2014b). Despite increasing awareness of carers' needs with the publication of the first and second National Carers' Strategies in 1999 and 2008 (Department of Health (DoH), 1999, 2008), many carers still receive little support with caring, with consequent effects on their mental and physical health (Newbronner et al. 2013).

The difficulties experienced by carers were reported in a recent survey (Carers UK, 2014b). Based on responses from 5,200 carers, one fifth reported that they were caring for more than 35 hours a week without any support. Nearly half stated that they had fallen ill and had no choice but to continue caring. Carers also described finding it difficult to maintain relationships and social networks, with more than half losing touch with friends and family. There is also evidence to suggest that carers are also more likely than non-carers to suffer from psychological difficulties and physical health problems (Moise et al. 2004). Furthermore, carers who suffer from less emotional distress report being more able to cope with the demands of caring and be more willing to continue providing care (Hirst, 2004). Carers can also suffer from financial hardship as a result of the potential loss of income from themselves and the person receiving care (O'Connor & McCabe, 2011). Additionally, those carers who continue in paid employment whilst caring are more likely to suffer faster declines in their mental and physical health than those leaving employment (Kenny et al. 2014).

Informal care is more frequently provided by females (Colombo et al. 2011), however there is a growing body of literature on gender differences in the caring experience. For example, there is evidence to suggest that males take a more task-oriented approach to providing care (Navaie-Waliser et al. 2002), whilst female carers report higher levels of emotional distress (Thompson, 2002). Furthermore, a recent systematic review found that male carers can perceive more barriers in accessing formal and informal support than females possibly because of their diverging attitudes to caring (Greenwood & Smith, 2015).

The literature presented above demonstrates the difficulties carers often encounter, however evidence is growing that caring can also be satisfying and fulfilling. Cohen et al. (2002) described the rewarding aspects to caring and reported almost three quarters of carers could identify at least one positive aspect to caring. These included companionship, finding it rewarding and that caring could be enjoyable. In a systematic review, Mackenzie and Greenwood (2012) described a range of positive experiences for carers of stroke survivors. These included witnessing the care recipients' progress, strengthened relationships, feeling appreciated and increased self-esteem. Further, carers who experience closeness (in the form of intimacy and companionship) are much more likely to feel they are coping and be less inclined to accept outside help (Murray & Livingston, 1998).

Given the numerous difficulties carers report, government policies and strategies have been implemented to try and help support them. The next section provides an overview of the English Government's recognition of the needs of carers.

1.1.3 The recognition of the needs of carers

The acknowledgment of the difficulties carers often experience described in the previous section is far from new. This section presents an overview of key points in the history of the development in the recognition of carers, with particular attention paid to the theoretical underpinning of what it means to be a carer and who in society is likely to provide care.

It has been suggested that gender, race and class distinguish who provides care in society and in what ways (Tronto, 1993). According to Tronto (1993) 'care work' has always been left to those who are less powerful, whilst those who are wealthier or in 'positions of superiority' pass caring work onto others. 'Positions of superiority' could be described in terms of family structure and assumed responsibilities, especially as caring has been traditionally seen as 'women's work' with the assumption females would carry out tasks associated with caring (Kantamneni, 2013). In England, the experiences of female carers were first brought to national attention by Mary Webster in 1963 (Cook, 2007). Mary Webster gave up her job as a Congregational Minister in 1954 to care for her elderly parents and, upon their deaths, reflected on the financial and social disadvantages due to caring (Barrett et al. 2013). These reflections led to her to campaign for the interests of carers and she formed the National Council for the Single Woman and her Dependants (NCSWD) in 1965. It was this organisation and the awareness it brought of carers' needs, which led to the Dependant Relative Tax Allowance (DRTA) being introduced in 1967 (Cook, 2007).

It was not until 1976 that the English government started recognising the contribution carers make to society and introduced the Invalid Care Allowance (ICA; The Social Security (Invalid Care Allowance) Regulations, 1976). This was the first benefit specifically for carers who could not work due to their caring commitments. However, it was restricted to those related to the person being cared for and not in full-time education, and was not available to married couples. In 1986 new legislation was passed in the Social Security Act, which allowed married women to claim ICA for the first time (Social Security Act, 1986). It was around this time that other countries were also starting to recognise the importance of carers and to develop national policies aimed at supporting them. For example, Sweden in 1964 implemented a national care allowance for parents of disabled children, and in 1973 the Australian government started paying the Domiciliary Nursing Care Benefit (DNCB) for carers of older frail people or those with disabilities (Yeandle et al. 2013).

Caring was, and by many still is, seen as a feminine role and an extension of the responsibilities of females in taking care of their families (Bond, 2001). Prior to 1948 and the introduction of the welfare state and NHS, women were usually expected to stay at home once married and care for their husband, children and often elderly relatives (Holden, 2001). It may be for this reason that many women may not identify themselves as carers or be identified by others as such (Twigg & Atkin, 1994). Holden (2001) suggested that although caring work can entail great physical strain, it has often been considered 'women's work', despite the association of femininity with weakness and dependence. Holden goes on to argue that feminist perspectives have identified how the word 'care' was often associated with core female identities, in that:

> "*good' mothers and 'dutiful' daughters give service to and care for their family because they care about them*" (p. 136).

Awareness of the amount of care being provided by carers increased during the early 1980s, with references surrounding caring made in literature and policy documents (Fine & Glendinning, 2005). One of the earliest definitions of caring was provided by Abrams (1978) in a report for Age Concern (now Age UK). In his survey of issues affecting older people he noted how those who were frail were often assisted by family members, calling them 'domestic caring agents'. Two years later a report by the Equal Opportunities Commission

(EOC, 1980) also noted how people, more often women, were providing care to elderly relatives. Whilst not defining them as 'carers', the EOC report does describe them as "*...adults who are responsible for the care of the sick, handicapped or elderly*" (EOC, 1980). Additionally, the EOC reported only two fifths of those providing care lived in the same home as the person receiving care, with the others facing daily travel expenses. However, the word 'carer' did not enter the English dictionary until the late 1980s (Barnes, 2006).

Recognition of the valuable contributions carers make to society increased during the 1980s. For example, the middle and latter part of the 1980s saw a push for the recognition of carers' rights from pressure groups, for example, the Carers National Association, which was a new organisation formed from the National Council for Carers their Elderly Dependants (formally the National Council for the Single Woman and her Dependants), and the National Association for Carers (Cavaye, 2006). The Carers National Association would later become known as Carers UK. The ability of carers to perform their caring role so that it meets the needs of the person being cared for was first described in the Disabled Persons (Services, Consultation and Representation) Act (1986). However, as argued by Twigg (1989), these policies were primarily concerned with the needs of the person being cared for and not those of carers. It was not until a decade later that legislation was passed which recognised the importance of carers to society and that they have needs of their own. The Carers (Recognition and Services) Act (1995), which came into force on 1st April 1996, entitled carers to an assessment of their needs and ability to provide care. The culmination of these government policies which identified the importance of carers to the English economy, coupled with lobbying by carer groups and organisations, led to the development of national carer strategies, the first of which was published in England in 1999. The key legislation affecting carers in England is:

- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Carers (Equal Opportunities) Act 2004
- Work and Families Act 2006
- The Equality Act 2010

1.1.4 National carers' strategies and policies 1999 to 2015

The beginning of this millennium saw an increase in policies and legislation aimed at supporting carers. The National Carers' Strategy for England (DoH, 1999), entitled 'Caring about Carers' had three main elements. These were to provide better information to carers, develop new support services and to focus on improving carers' health. As part of this 'carers' package' it was proposed that there would be more support for neighbourhood services, including carers' centres. Importantly for the current research, the development of services which used technology to support carers, including telephone befriending, were to be delivered. The strategy also suggested that local support for carers (carers' centres or other community social support, including voluntary sector organisations) could be delivered by befriending services which could provide emotional support or a 'listening ear'. This was supported by evidence that more than half of carers viewed local carers' centres as an opportunity to find someone who listens to them and more than a third felt it would offer the opportunity to make links with other carers. The overall conclusion of this strategy was that carers needed caring for and that improving their quality of life was paramount.

Progressing with implementing the aims of the 1999 carers' strategy and improving quality of life for carers, The Carers (Equal Opportunities) Act (2004) legislated that carers were not to be disadvantaged due to their caring responsibilities and to ensure they were informed of their right to an assessment. It also aimed to help support the provision of services to carers, which was later documented in the 2008 National Carers' Strategy (discussed later in this chapter). It argued that:

> "*... there should be co-operation between authorities in relation to the provision of services that are relevant to carers*" (DoH, 2008a, p. 26).

Three years later, Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care (HM Government, 2007), set out objectives to give people with disabilities and their carers more control over their lives by developing a more personalised social care system. It also stated that carers should be treated as experts in helping to decide which services were best for the person they care for, and that advice, information and advocacy, potentially delivered through the voluntary sector, should be provided to carers. Giving carers more control and developing more personalised services features prominently in subsequent policy documents.

The move towards supporting a policy of 'personalisation' was evident in the White Paper 'Our health, our care, our say: a new direction for community services' (DoH, 2006). One of its objectives was to provide carers of people with long-term conditions with information about where to access peer support networks. It is first documented here that the 1999

National Carers' Strategy would be updated with the offer of a 'new deal for carers', with the focus being on improving their health and well-being. Subsequently, an updated version was published (DoH, 2008a) with its vision described as:

> "*...by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen*" (p. 9).

The specific aims were that by 2018:

- *Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;*
- *Carers will be able to have a life of their own alongside their caring role;*
- *Carers will be supported so that they are not forced into financial hardship by their caring role;*
- *Carers will be supported to stay mentally and physically well and treated with dignity;*
- *Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes* (DoH, 2008, p. 16).

One of the commitments was to provide carers with better access to emotional support which could be provided by the voluntary sector. There was also a drive to gather data about carers to inform commissioners and policy makers better about how best to provide improved support. Among the identified priorities from 2011 onwards was to provide specialist services for carers in every community and make them easier to access. One of the ways it planned to do this was by providing funding for the development of befriending services. There was also the commitment to encourage the commissioning of services from the voluntary sector, such as peer support, as many carers said they preferred to deal with voluntary sector services rather than statutory services. It was also emphasised that services provided by the voluntary sector could potentially offer flexibility for carers in accessing support.

Despite the updated National Carers' Strategy (DoH, 2008a), the provision of information and advice was still identified as needing improvement two years later. In a household survey commissioned by the Department of Health, a quarter of carers in England reported it as fairly difficult or very difficult to find the information they need (The NHS Information Centre, Health and Social Care, 2010). Building on the 2008 National Carers' Strategy and its updated version in 2010 (DoH, 2008a; 2010a), the Carers' Strategy: Second National Action

Plan 2014-2016 (HM Government, 2014) reported the progress in developing carer services since 2008 and the actions planned through to 2016. Four priority areas for action were identified:

- Identification and recognition of carers
- Realising and releasing potential of carers
- A life alongside caring
- Supporting carers to stay healthy

The 'identification and recognition' action priority aimed to support people with caring responsibilities to identify themselves as carers so they could gain access to appropriate support and services. The 'realising and releasing potential' priority area related to helping carers to stay in employment for as long as possible, with the assistance of their employer and local services. The plan provided evidence that whilst eight in ten employers offered flexible working arrangements for carers, less than half of carers reported this as being available in their work place. Promoting flexible working and helping carers to stay in employment were some of the key aims of the strategy. Given how the circumstances of carers vary, it aimed to personalise support and provide good quality advice and information. It was emphasised that providing carers with good quality information as early as possible could reduce the likelihood of financial hardship and help carers manage other areas of their lives 'alongside' their caring role. It was restated that:

> "*We need to continue to prioritise supporting carers of all ages to manage their caring responsibilities alongside other aspects of their lives*" (p. 42).

The final priority area was to support carers in staying healthy and highlighted that:

> "*The provision of information and advice is key in supporting carers to look after their own physical health at an early stage of caring and throughout their caring roles*" (p. 54).

However, it does not state ways in which it aimed to improve the provision of advice and information and there is no mention of befriending or peer support services. It described other ways in which support for carers to maintain their health and well-being would be implemented, such as helping people to identify themselves as carers at an early stage, supporting them to return to education and work and helping them to live a life alongside caring.

More recently, The Care Act (2014) expanded existing legislation regarding a number of issues for people with disabilities and their carers. The Act was designed:

> "*...to make provision to reform the law relating to care and support for adults and the law relating to support for carers...*" (The Care Act, 2014, chapter 23, p. 1).

One of the main points of the Bill was that it:

> "*...treats carers as equal to the person they care for – putting them at the centre of the law and on the same legal footing*" (HM Government, 2013, p. 10).

This builds upon The Equality Act 2010, which prohibits discrimination against carers, for example, when using public services or when in employment. Factsheet Eight published by the Department of Health (DoH, 2014), provided an overview of the Care Act 2014 and carers legal rights. It stated that local authorities had a responsibility to assess carers' needs, without the carer "*needing to provide substantial care on a regular basis*" to qualify for an assessment (p. 1). This was an improvement on the Carers and Disabled Children's Act (2000) which included the vague phrase "*... provide a substantial amount of care on a regular basis...*" in order to qualify for a carers' assessment (Chapter 16, p. 1). The Care Act (2014) also highlighted that carers' needs should be treated as equally important to those they care for and that it would be up to the local authority to take care of the individual needs of each carer with a support plan. Most provisions in the Care Act (2014) came into force on April 1st 2015, including the ways in which local authorities determine eligibility for support and then undertake assessments of need. The remaining part of The Care Act (2014) will come into force in April 2016, including the regulations on local authorities' charges for residential and community care.

1.1.5 Volunteer mentoring in public policies

The National Carers' Strategies (DoH, 1999, 2008) focused attention on the specific needs of carers and the services best placed to support them. Located within these policy documents are references to supporting carers with the help of volunteers in the form of peer support or befriending interventions, in particular the National Carers' Strategy (DoH, 2008a) and the National Dementia Strategy (DoH, 2009). The idea behind these services was to help people stay supported in the community, and focus on delivering the interventions with the help of volunteers (Mead et al. 2010). However, evaluations of these services (discussed later in Chapter Two) yielded equivocal findings (Clarke et al. 2013; Yeandle & Wigfield, 2011).

Despite this, befriending and peer support have continued to be referred to in policy documents, but with little evidence as to the benefits for carers or exploration of sub-groups of carers such as those supporting people with dementia who are known to have poorer health (HM Government, 2010, 2012a).

This therefore was the basis for this research, which aimed to address these evidence gaps through the investigation of the experiences of volunteer mentoring for both carers of people with dementia and also the volunteers.

1.2 Study aim and research questions

The aim of this research was to investigate the impact of volunteer mentoring on carers of people with dementia, how volunteers experienced delivering the support and the processes by which carers and volunteers developed mutually beneficial relationships. The research had two interconnected phases. Phase One started with a systematic review which was used to inform data collection of a survey of volunteer mentoring services. The findings from Phase One in turn informed Phase Two, which included the main research study looking at the impact of volunteer mentoring on carers and the experiences of volunteer mentors.

The research addressed the following questions:

1. What is the range of volunteering mentoring services in England offered to carers of people with dementia?
2. What do the processes underlying volunteer mentoring involve?
3. What types of relationships do carers of people with dementia and volunteers form?
4. What is the evidence for the impact of volunteer mentoring for carers of people with dementia?
5. What are the volunteers' experiences and perceptions of volunteer mentoring?

Research question 1 was addressed by conducting a survey of volunteer mentoring services in England (Chapter 5). This, coupled with the systematic review (Chapter Four) comprised Phase One of this thesis. The combined findings from Phase One informed the development of Phase Two of the research, which addressed research questions 2, 3, 4 and 5. Next, the philosophical and epistemological underpinnings of the thesis are presented.

1.3 Philosophical and epistemological underpinnings of the thesis

The philosophical assumptions of all research are primarily concerned with ontology, epistemology and the research questions (Creswell & Plano Clark, 2011). The researcher's assumptions about ontology and epistemology then inform methodological choices, from the theory through to data collection and analysis (Grix, 2004). These assumptions are a basic set of beliefs that guide enquiry (Creswell & Plano Clark, 2011). Terms which are often used to describe these assumptions are 'world views', 'paradigms' or 'belief systems' (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 1998; Tashakkori & Teddlie, 2010).

There are four main world views in which social science researchers conduct research: post-positivism, constructivism, transformative and pragmatism (Mertens, 2005). Creswell and Plano Clark (2011) note that all four world views have common elements (ontology, epistemology, axiology, methodology and rhetoric), but that their stances differ on these elements. For pragmatism, the world view which underpinned this thesis, Creswell and Plano Clark suggest that ontology (what is the nature of reality?) has both singular and multiple realities with researchers providing multiple perspectives on hypotheses tested. Epistemology (what is the relationship between researcher and that being researched?) is based around practicality, in that data are collected based on what works best to answer the research questions. Axiology (what is the role of values?) includes both biased and unbiased perspectives, as opposed to research which is purely quantitative which would involve procedures to try and eliminate bias. Methodology (what is the process of research?) focuses on combining both quantitative and qualitative data and then mixing them to provide more robust conclusions. Finally, for rhetoric (what is the language of research?) a formal style of writing is used. As previously mentioned, this thesis is underpinned by pragmatism (Tashakkori & Teddlie, 2003) which lends itself to mixed methods research. An overview of pragmatism, its history and how it relates to all phases of this research is presented below.

1.4 Pragmatism

A concise overview of the history of pragmatism was presented by Maxcy (2003), who divided the history of pragmatism into two distinct time periods. Firstly, Maxcy described the 'early period' (1860 to 1939) and secondly the 'later period' (1960 to present). this later phase is often referred to as the neo-pragmatic period. Maxcy argues that the foundations of pragmatism as a philosophical movement can be traced back to the 19th Century with the work of American Charles Sanders Pierce. This was then developed in the early 20th Century by other academics, such as William James, Charles Dewey, George Herbert Mead and Arthur Bentley. They challenged the notion that research could only be carried out with the use of single method. In particular, Maxcy highlights that pragmatism was likely first used in research methodologies by Pierce in 1861 or 1862. It was also Pierce who gave pragmatism its name.

Even though the idea of using a pragmatic approach to research has been first proposed 150 years ago, it is only more recently that it has become widely used in mixed methods research (Creswell & Plano Clark, 2011). Teddlie and Tashakkori (1998) formally linked pragmatism with mixed methods research by highlighting a number of crucial points. Firstly that pragmatism rejects the 'incompatibility thesis' which was at the heart of the previously mentioned paradigm wars. Secondly, they refer to 'dictatorship of the research question', in that the research question is more important than either the method or paradigm used. Thirdly, pragmatists reject the forced choice between post-positivism and constructivism and embrace either epistemologies or a middle ground between them. Fourth, pragmatists avoid using metaphysical concepts such as 'truth' or 'reality'. Further highlighting the connection between mixed methods research and pragmatism, Nastasi et al. (2010, p. 308-309) state that:

> "*...pragmatism places importance on the practical aspects of research (e.g. what works best for answering the research question), the context (e.g., what is most appropriate given the contextual conditions), and potential consequences of research (e.g., the social or political implications)*"

They also argue that pragmatism is the most common paradigmatic foundation for conducting mixed methods research. This is supported by Howe (1988) who argues that mixed methods research is most likely to be conducted by pragmatists by stating that researchers should forge ahead "*with what works*" (p. 15).

As mentioned previously, pragmatism underpins this thesis. The primary importance was given to the research questions (section 1.2) and how best to answer them. A pragmatic approach was adopted at all stages of empirical research throughout the thesis. It begins with Phase One with a systematic review (Chapter Four), where evidence was not excluded based on the study methods used. Equal weighting was given to the findings of included quantitative and qualitative studies in understanding what was already known about volunteer mentoring. The systematic review findings helped to shape the research questions and aims for the survey of services (Chapter Five). Continuing with the pragmatic approach, no priority was given to either quantitative or qualitative data collection for the survey, with the researcher developing the research questions based the pragmatic world view of what works best to answer the research questions.

1.5 Thesis methods

This thesis used a mixed methods approach in order to answer the research questions. Mixed methods are used throughout the thesis, from a systematic review (Chapter Four) which includes both quantitative and qualitative studies, to a survey of services which used a questionnaire to collect multiple types of data, to Phase Two of this research which used a sequential explanatory mixed methods design. Mixed methods were chosen over either quantitative or qualitative methods alone for a number of reasons. For example, understanding the impact of interventions would suggest quantitative measures were required. However, given that there is little evidence for the impact of volunteer mentoring for carers of people with dementia, exploring the carers' experiences of accessing these services and whether they feel they are doing what they set out to needs the use of qualitative methods. There were pragmatic reasons for choosing the type of data collection methods used in the qualitative phase of the mixed methods research (Phase Two). For example, one-to-one interviews were deemed to be more appropriate than focus groups due to the potentially sensitive nature of some of the topics likely to be discussed by participants. The use of mixed methods and how it related to Phase Two of this research is explained in greater detail in Chapter Six. Even though robust reasons for using mixed methods in this thesis have been presented, there are challenges involved with this type of study design.

Whilst mixed methods research encounters many of the same issues as studies involving only quantitative or qualitative methods, it also has its own unique issues such as a lack of philosophical foundations and the perceived lack of compatibility between quantitative and qualitative methods (Burke Johnson & Onwuegbuzie, 2004). This was described by Small (2011, p. 77) who stated:

> "*Some authors have argued that combining quantitative and qualitative perspectives is not possible without contradiction, because different methods reflect different epistemologies, which, by definition, hold different assumptions about the nature of truth*".

However, Burke Johnson et al. (2007) argues "*mixed methods research is likely to provide superior research findings and outcomes*" when used appropriately depending on the initial research questions. This could largely be due to many of the limitations of using only quantitative and qualitative methods cancelling each other out as the results are triangulated. Qualitative findings can add meaning to the quantitative data and quantitative data provide validation for the qualitative findings (Creswell & Plano Clark, 2011). This flexibility enables the researcher to draw more comprehensive and wide ranging conclusions about the topic being studied (Creswell & Plano Clark, 2011).

Further, Bryman (1988, p, 125) suggested that mixed methods research can offer a more complete overview of the topic being investigated, "*when quantitative and qualitative research are jointly pursued, much more complete accounts of social reality can ensue.*" However, as mentioned by Hesse-Biber and Burke Johnson (2013), there are barriers to successfully conducting mixed methods research.

Whilst difficulties in recruiting adequate numbers of participants is a common issue with many research studies (Patel et al. 2003; Ross et al. 1999), it should be noted that a mixed methods design puts more stress and burden on participants than research involving only quantitative or qualitative methods and clear justification is needed for its use (Andrew & Halcomb, 2009). It has also been shown to be "*complex, time consuming and potentially prone to fragmentation*" (Robinson, et al. 2011, p. 13). However, Robinson et al. (2011) also argue that a flexible and pragmatic approach is the best fit for successful mixed methods dementia research due to the challenges involved with data collection. Next, the structure of the thesis is described in greater detail and the contents of each chapter are documented.

1.6 Structure of the thesis

The research begins with Chapter Two which examined the literature concerning carers of people with dementia. The background to the effects of dementia on those with the condition is presented, followed by the impact on carers' psychosocial and physical health. Next, interventions which have been developed in order to help support carers are explored, followed by an examination of service use by carers of people with dementia, with a focus on the potential barriers in accessing support. Finally, the English government's National Dementia Strategy (DoH, 2009) is examined and the extent the available literature is used to promote the development of services is explored.

Chapter Three explores the background to volunteering from a UK perspective. Attention is drawn to The Conservative Government's Big Society agenda, with an examination of the potential impact on volunteering in the UK. This is followed by an investigation of the reasons why people choose to volunteer, including benefits to mental and physical health, and the potential role of and impact on former carers in providing volunteer mentoring support. Next, the available literature concerning the impact of the various types of volunteer mentoring services in a variety of populations is explored. Chapter Three ends by describing Homophily Theory (Lazarsfeld & Merton, 1954) and Social Exchange Theory (SET-Emerson, 1976). These theoretical perspectives were used to explore and explain the findings of this research.

Chapter Four marks the beginning of Phase One and documents the systematic literature review. The review explored the literature for primary research studies investigating the impact of volunteer mentoring on carers of people with dementia or volunteers. The review found four studies fitting the inclusion criteria; three on peer support and one on befriending. No studies exploring the impact on volunteers were identified. The results showed the importance of experiential similarity and a lack of need to 'match' carers with volunteers on an extensive set of demographic criteria. Overall, it was reported there was insufficient evidence for the effectiveness or otherwise of volunteer mentoring for carers of people with dementia.

Chapter Five presents a survey of services which was also part of Phase One. This aimed to answer research question one, which was concerned with investigating the range of volunteering mentoring services offered to carers of people with dementia in England. It explored how the services operate and highlighted similarities and differences between them. Undertaking this survey was important because of the dearth of studies identified in the systematic review. The findings showed services tend not to use a theoretical basis for carer 'matching' and do not recruit volunteers based on prior caring experience; something the systematic review suggested was important. Given the differences between how the services were operating and what the available literature showed as important (e.g. experiential similarity), it was necessary to conduct research which could clarify this and provide guidance for policy and practice.

Chapter Six marks the beginning of Phase Two, which aimed to answer research questions two, three, four and five (section 1.2). Chapter Six describes in detail the mixed methods approach that was used for this phase. A sequential explanatory design was chosen, with a quantitative phase followed by a qualitative phase. Carers from the quantitative phase took part in the qualitative phase. As no previous research was identified that investigated the experiences of volunteer mentors, this was explored qualitatively using semi-structured interviews.

Chapter Seven documents the findings of Phase Two. First, the quantitative results are presented, followed by the qualitative findings from carers and volunteers. Quantitative results highlighted little impact on carers with regards to depression, anxiety and loneliness. Statistically significant results were found for perceived social support. Qualitative findings showed how carers valued talking to someone with experiential similarity and felt able to release emotional distress. Volunteers also talked about the importance of experiential similarity and the positive impact the support had on carers. They also described how carers and volunteers engaged in mutually supportive relationships and the benefits volunteering had on them.

Chapter Eight contains the discussion which explores the findings from Phase Two and how they relate those findings from Phase One. It is argued the findings support the theories presented in Chapter Three (Homophily Theory and SET) for understanding the mechanisms by which volunteer mentoring works and provides mutual benefits for both carers and volunteers. It is also argued that the synthesis of quantitative and qualitative data provided a more complete understanding of the potential benefits of volunteer mentoring than using one method. The thesis ends with the overall conclusions and recommendations for policy and practice.

2 Chapter Two: Carers of people with dementia

2.1 Introduction

This chapter provides background literature about carers of people with dementia. Whilst carers generally supporting people with various health conditions experience many of the same difficulties, evidence suggests that carers of people with dementia often suffer more stress and burden than those caring for people with other health conditions (Moise et al. 2004).

The chapter starts by providing information about dementia, for example; the incidence, prevalence and symptoms. It then turns to the experiences of carers of people with dementia, followed by an overview of the evidence regarding the interventions aimed at helping support carers. The chapter ends with an examination of the English National Dementia Strategy (DoH, 2009), followed by an exploration of the evidence for the effectiveness of carer peer support services set up following the strategy.

2.2 Dementia

Worldwide dementia is increasing. It was estimated in 2010 that 35.6 million people were living with the condition and a further 7.7 million were diagnosed annually, which represented one new diagnosis every four seconds (WHO, 2012). Approximately 2.3 million of those diagnoses were in Europe (WHO, 2012). As of 2015, the number of people living with dementia had increased to 46.8 million, with an expectation there would be 9.9 million people diagnosed in 2015 alone (Prince et al. 2015). The rising rates of dementia are of international concern, with estimates suggesting 131.5 million people will be living with the condition by 2050 (Prince et al. 2015).

In the UK, it was estimated that there were 821,884 people living with dementia in 2010, representing 1.3% of the population (Luengo-Fernandez et al. 2010). This is expected to increase to 850,000 in 2015 (Alzheimer's Society, 2014b) and rise to over one million by 2025 (Knapp et al. 2007). Recent research has suggested that one in every three people born in 2015 will develop dementia during their lifetime (Lewis, 2015). The prevalence and incidence of dementia are greater in people over the age of 65, with a peak incidence rate in Europe and North America occurring in those aged between 80-89 years (Sousa et al. 2009; WHO, 2012). The prevalence of dementia rises with age, doubling with every five year increase (Knapp et al. 2007). The incidence of dementia is also greater among females than males, with the greatest differences between genders being seen above the age of 80 (van der Flier & Scheltens, 2005).

Worldwide, it was estimated that dementia had an economic cost of US$604 billion in 2010, with 70% of that cost occurring in Western Europe and North America (Wimo et al. 2013). This figure had increased to US$818 billion as of 2015 and was projected to grow to US$2 trillion by 2030 (Prince et al. 2015). It was estimated that the economic burden of dementia to the UK economy was approximately £23 billion per year in care costs and lost productivity in 2010. This was twice as much as cancer, three times as much as heart disease and four times greater than stroke (Luengo-Fernandez et al. 2010).

Alzheimer's disease is the most common type of dementia, accounting for between 60-70% of all diagnoses (WHO, 2012). The other relatively common types are vascular dementia, mixed dementia (combined Alzheimer's disease and vascular dementia), dementia with Lewy bodies and frontotemporal dementia (WHO, 2012). Common symptoms include memory problems, difficulty concentrating, loss of language skills, difficulty with visuospatial skills and loss of orientation (National Institute on Aging, 2015). Other common debilitating symptoms which can affect up to nine in ten of people with dementia include incontinence, decreased mobility, agitation and aggressive behaviour (Alzheimer's Society, 2014c). These symptoms are often referred to as the behavioural and psychological symptoms of dementia (BPSD) and are associated with high levels of distress for both people with dementia and their carers (Finkel et al. 1997).

Whilst dementia is a progressive condition, it affects people in different ways, for example some people deteriorate faster than others and some may not have all of the symptoms commonly associated with dementia (WHO, 2012). However, the progression of dementia can usually be described as following three stages:

1. Early stage: usually occurs within the first two years. People with dementia begin to have difficulty with short-term memory, carrying out complex household tasks and handling personal finances. They can also experience changes in mood and behaviour (for example: becoming less active, depressed or agitated) and potentially become lost in familiar places.
2. Middle stage: usually occurs between second and fifth years. People may start becoming very forgetful, become lost at home and in the community, have increasing

difficulty with communication and may need assistance with personal care. They may be unable to live alone without support and may experience an increasing number and severity of BPSDs.

3. Late stage: fifth year and after. People are usually unaware of time and place, have difficulty in understanding what is happening around them, are unable to eat without assistance, have increasing need for self-care and suffer from increasing behavioural changes. They may also fail to recognise friends and family (WHO, 2012).

Dementia usually affects older people over the age of 65, with prevalence doubling with every five year increase in age (ADI, 2009). Median survival times from the onset of dementia are approximately 4.1 years in males and 4.9 years in females in those aged 65 or over (Xie et al. 2008). Those aged between 60 and 65 years have the longest survival rates, with a median of 6.7 years, compared to 1.9 years in those aged 90 or over (Rait et al. 2010). However, this could be at least partially due to the lower life expectancy for those over the age of 90.

The International Classification of Diseases 10 (ICD-10, WHO, 1993) specifies that a diagnosis of dementia can be based on evidence of decline in memory and a decline in other cognitive abilities, characterised by deterioration in judgement and thinking which should have been present for at least six months. A person with dementia may experience changes with their emotions (described as ‘emotional lability’ or irritability) or changes in their social behaviours. The severity of dementia is classified as mild, moderate or severe, based on the results of neuropsychological tests, such as the Mini Mental State Exam (MMSE, Folstein et al. 1975), which is used to examine the severity of cognitive decline. Upon diagnosis, a person with dementia in the UK may be offered medication to help with the symptoms of the condition. Although there are currently no medications or other treatments which can slow or stop the progression of dementia, there are some medicines which can help with retaining and forming memories (Moise et al. 2004).

The National Institute for Health and Care Excellence (NICE, 2007) recommends the prescription of donepezil, galantamine and rivastigmine, which are classed as acetylcholinesterase (AChE) inhibitors. These AChE inhibitors work by increasing the amount of acetylcholine (ACh) in the brain, which can help treat some of the symptoms of dementia, such as memory problems (Food and Drug Administration (FDA), 2012). However, in the UK these prescription drug treatments are mostly limited to those with a diagnosis of mild or moderate Alzheimer's disease, with the exception of memantine which is licenced for use in those diagnosed as having 'severe' Alzheimer's disease (NICE, 2007). These medications can improve the quality of life for those with dementia for an extended period time (Raina et al. 2008). However, it has been estimated that only about a third of people with dementia receive a diagnosis, potentially limiting their access to medication and support for carers (DoH, 2009).

It has been estimated that approximately one half of all people who have dementia over the age of 65 live in their own homes in the community in the UK (Prince et al. 2014; Macdonald & Cooper, 2007). However, up to nine in ten of people in the final stages of dementia reside in a long-term care facility (Smith et al. 2000). People with dementia move into long-term care often due to the progressive physical, mental and cognitive difficulties they may have, which can lead to a loss of independence and ability to take care of themselves (ADI, 2013). Recently, English government policy has moved to help keep people supported in the community and reduce the numbers entering long-term care (DoH, 2009). The progressive nature, BPSD symptoms of dementia and the desire to keep people at home have implications for carers supporting those living with the condition in the community.

In the next section the experiences of carers of people with dementia are examined, with the focus on the psychosocial and physical effects caring can have.

2.3 Experiences of carers of people with dementia

There are known consequences for the mental, physical and social aspects of the health of carers of people with dementia and they are regarded as under more mental and physical strain than carers of people with other conditions (Ballard et al. 2000; Baumgarten et al. 1992; Donaldson et al. 1997; Moise et al. 2004). This section explores the experiences of carers of people with dementia with the focus on the potential impact on their mental, social and physical health.

2.3.1 Impact on mental health

Carers of people with dementia are often found to have an increased risk of burden, depression and anxiety than non-carers due to the increased strain of caring (Etters et al. 2008; Kim et al. 2011; Leggett et al. 2011; Mahoney et al. 2005; O'Shea, 2003; Pinquart &

Sörensen, 2003). Despite the word 'burden' often being used in research involving carers, it is a concept which encompasses numerous factors and is difficult to define (Bastawrous, 2013). However, for the purpose of this research when discussing carer burden, the following definition described by Kim et al. (2011, p. 846) is adopted:

> "(carer burden is a) *multidimensional response to the negative appraisal and perceived stress of resulting from taking care of an ill individual. Burden threatens the physical, psychological, emotional and functional health of caregivers*".

There are a number of risk factors for carer burden and stress, including being female, low level of educational attainment, living with the care recipient, higher number of hours spent caring, depression, social isolation, financial difficulties and a lack of choice in being a carer (Adelman et al. 2014; Barusch & Spaid, 1989; Navaie-Waliser et al. 2002; Qadir et al. 2013). Carers of people with dementia report consistently high levels of burden, which continues to rise over time as the person with dementia becomes increasingly ill (Brodaty et al. 2014). Female carers of people with dementia are also more likely to report higher levels of burden than male carers, regardless of whether they come from low, middle or high income countries (Gallicchio et al. 2002; Prince et al. 2012). Evidence also suggests female carers are at a greater risk of emotional distress than male carer (Hepburn et al. 2002; McDonnell & Ryan, 2014).

Carer burden has been associated with poor outcomes such as depression and impaired quality of life (Schulz & Sherwood, 2009). The strongest predictors of carer burden and depression are the BPSD the person with dementia experiences (Covinsky et al. 2003; Pinquart & Sörensen, 2003). Personality changes of the person with dementia can cause a sense of loss or bereavement or 'living bereavement' for carers (Taylor, 1987). This grief can also be a factor in increased carer depression, with 'anticipatory grief' (occurring before the person with dementia has died) being greatest in spousal carers (Chan et al. 2013). Spouses can also find it difficult to adjust to an increasingly unequal relationship and deteriorating levels of communication (Bunn et al. 2012; Evans & Lee, 2014).

Greater depressive symptoms in carers have been associated with increased sleep disturbance (Beaudreau et al. 2008). The need to be vigilant to safeguard the person with dementia and worry about current and future events have also been reported by carers as issues affecting their sleep (Twigg & Atkin, 1994; Simpson & Carter, 2013).

Despite the overall negative impact of caring on carers, some groups are at greater risk of being adversely affected. For example, in the United States (USA) fewer depressive symptoms have been reported in carers with larger social support networks and higher levels of education (Piercy et al. 2013). Again in the USA, White carers of people with dementia have been shown to report greater levels of depression, stress and burden than African American carers (Covinsky et al. 2003; Janevic & Connell, 2001; Lawton et al. 1992; Pinquart & Sörensen, 2005). It has also been reported that spousal carers report more depressive symptoms and greater financial burden than other carers (Pinquart & Sörensen, 2011).

Variations in the reported burden and mental health of carers are also affected by the stage of the condition the person of dementia is experiencing. For example, self-care of carers has been shown to gradually decrease in line with the increasing BPSD the person with dementia exhibits (Haley & Pardo, 1989). However, it has been suggested that the majority of carers experience difficulties in caring for a person with dementia, regardless of the stage of the condition (Zwaanswijk et al. 2013).

Along with increasing burden and mental health difficulties, carers can also experience social isolation and loneliness. The next section examines this in detail before exploring the impact of caring on physical health.

2.3.2 Impact on relationships and social activity

Although the terms loneliness and social isolation are often used interchangeably (Windle et al. 2014), there is a distinct difference between the two, with one not necessarily leading to the other (Table 1). For example, Ubido and Scott-Samuel (2014) differentiate between them:

> "*Loneliness is a psychological state. It is a subjective, negative feeling associated with lack or loss of companionship. If you feel lonely, you are lonely*" (p. 4).

Whereas they describe social isolation as:

> "*...a sociological category relating to imposed isolation from normal social networks. This can lead to loneliness and can be caused by loss of mobility or deteriorating health*" (p. 4).

Bolton (2012) argues that it is possible to be socially isolated and not lonely, equally it is possible to feel lonely despite frequent contact with family and friends.

Loneliness is common, with between 15% and 30% of the general population experiencing long-term loneliness which impacts on their health and well-being (Hawkley & Cacioppo, 2010). Those aged under 25 and over 55 are most likely to report feeling lonely (Hawkley & Cacioppo, 2010). Higher levels of reported loneliness have been correlated with increased incidence of mental illness, particularly depression (Cacioppo et al. 2006; Liu et al; 2014). This is concerning, as research has shown that eight in ten carers report being lonely as a result of their caring role (Carers UK & Age UK, 2015). Along with increased loneliness, carers often report being socially isolated as a result of caring, with nearly three in ten (57%) losing touch with family or friends (Carers UK, 2015).

Table 1. Definitions of loneliness and social isolation

	Definition
Loneliness	A subjective psychological state. For example, a person can feel lonely despite support from family and friends. For example: "*Loneliness is a feeling of deprivation caused by the lack of certain types of human contact: the feeling that someone is missing*" (Gordon, 1976, p. 26).
Social isolation	Physical isolation from others which can result in a person not being able to engage in desired social activities. It can also lead to feelings of loneliness. For example: "*…a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling and quality relationships*" (Nicholson, 2009, p. 1346) or "*…the absence or paucity of social relationships or ties between an individual and others, namely family and/or friends*" (Cloutier-Fisher et al. 2006, p.13).

Carers are more likely to be more socially isolated than non-carers, due partly to a lack of social support and difficulty in being able to leave the house (Carers UK, 2014b). Socially isolated carers are at risk of being further negatively impacted by the stressors of caring (Scharlach et al. 2001). There is evidence to suggest carers of people with dementia are at an increased risk of social isolation and loneliness when compared to carers of people with other conditions or non-carers (Beeson, 2003; Kaiser & Paneyres, 2007). There are numerous potential reasons for this, for example, feeling stigmatised by the diagnosis of dementia, leading to isolation as a result of losing contact with family and friends (ADI, 2012; Shanley et al. 2011). Also, carers of people with dementia tend to sacrifice both their hobbies, meeting with friends and family, and to reduce or give up employment, all of which can add to social isolation and reduce social support (Brodaty & Donkin, 2009; Schulz & Martire, 2004). Increasing isolation from others may increase loneliness for carers of people with dementia, as companionship and friendships have been shown to be protective factors (Rook, 1987; Hall-Elston & Mullins, 1999).

2.3.3 Effects of caring on physical health

Along with a risk of deteriorating mental health and social activity, there is also evidence to suggest carers of people with dementia are at risk of greater physical ill health when compared to carers of people with other conditions and non-carers (McConaghy & Caltabiano, 2005; Sörensen et al. 2006; Vitaliano et al. 2004). In a meta-analysis of studies investigating carer ill health (Pinquart & Sorenson, 2007), it was reported that carers of people with dementia were most likely to have physical health problems as a result of the specifically stressful nature of their caring responsibilities. Similarly, Etters et al. (2008) found that the difficult and often challenging situations caring for a person with dementia presents can lead to many of the physical and mental health issues carers encounter. The authors suggest appropriately tailored services need to be developed to improve health and well-being of carers.

Some carers also report a deterioration of their own long-term health conditions as a result of the demand of caring for a person with dementia (Brodaty & Green, 2002). For example, a third of carers are at risk of becoming malnourished and one in 20 is currently malnourished (Rullier et al. 2014). Another study puts the risk of malnourishment as high as four in ten for male carers and over half for female carers of people with Alzheimer's disease (Puranen et al. 2014). Other physiological issues which can affect carers include increased cortisol levels (Stalder et al. 2014; de Vugt et al. 2005), impaired immune system and hyperglycaemia (Papastavrou et al. 2007). These do not affect all carers equally. For example, in the USA, African American carers have been found to be at greater risk of developing one or more of these physical health issues when compared to White carers (Haley et al. 1996; Wallsten, 2000). Carers of people with dementia are also more likely to take prescribed medication and more frequently visit their general practitioner (GP) than non-carers (Brodaty & Hadzi-Pavlovic, 1990).

2.3.4 Financial impact of caring for a person with dementia

There are challenges and difficulties which are common to most carers (Coe & van Houtven, 2009; Pinquart & Sörensen 2003; Shaw et al. 1997). However, carers of people with dementia can often face greater financial hardship (Carers UK, 2008) than carers of people with other conditions. Further still, carers of people with young onset dementia (under the age of 65) tend to experience greater difficulties, for example work related and financial issues (Svanberg et al. 2011), than those caring for an older person with Alzheimer's disease (Nicolaou et al. 2010).

This section has presented evidence for the increased stress, isolation and mental and physical health difficulties carers of people with dementia can experience. The next section follows on from this to examine the types of support offered to carers of people with dementia and evidence of their impact.

2.4 Psychological and social support

This section explores approaches to psychological and social support available to carers of people with dementia and the evidence for their impact. Psychosocial interventions have been described as:

> "*...psychological interventions specific in the UK Department of Health review of psychological therapies, social interventions such as social skills training and befriending and packages of interventions that have a psychosocial focus (even if they also include some more biological interventions)*" (Ruddy & House, 2005, p. 3).

Psychological and social support interventions aimed at keeping carers supported in the community include Admiral Nurses, psychoeducation, counselling, support groups and respite (Bunn et al. 2015; Cooke et al. 2001; Livingston et al. 2014; Scott et al. 2015; Sörensen et al. 2006). Although many of these interventions are often found to have little positive impact on coping ability and health (Peacock & Forbes, 2003; Thompson et al. 2007), there is evidence to suggest some offer better outcomes than others. For example, some carers accessing psychotherapy interventions developed improved coping skills (Mittleman et al. 1993) and educational interventions have been shown to reduce carer burden (Devor & Renvall, 2008). Participation in structured support groups (with professional facilitators) has also been shown to offer reductions in self-reported depression when compared to control groups (Chu et al. 2011).

Carers of people with dementia may find themselves increasingly isolated making it difficult to share their concerns with others (Brodaty & Hadzi-Pavlovic, 1990). This can be especially difficult if the person with dementia was the person they would usually talk to (Nolan & Keady, 2001). In particular, it has been suggested that carers need to talk to others to reduce loneliness or to 'let off steam' during times of crisis (Twigg & Atkin, 1994). For carers of people with dementia it may not be possible to talk to the person being cared for which can compound the sense of isolation and loneliness they may feel (Twigg & Atkin, 1994). Social support, in particular support groups have been shown to offer carers the chance to gain mutual support from people in similar situations (Twigg & Atkin, 1994). However, it has also been shown some carers do not want to access support groups (Demers & Lavoie, 1996), with Twigg and Atkin (1994) reporting they do not want to hear about other people's difficulties as they feel they have enough of their own. However, it has been shown how the exchanging of advice and information between carers at support groups offers a source of learning and support (Twigg & Atkin, 1994). This is important since a lack of information or information which is too technical or inaccessible can lead to carers feeling helpless and unable to continue caring (Gilliard, 2001).

Along with social support in a group format, there is evidence to suggest one-to-one support offers beneficial outcomes, for example reducing depressive symptoms and emotional distress (Mead et al. 2010). Despite this, in a systematic review of the literature, Dickens et al. (2011) found one-to-one social support interventions which are designed to reduce isolation and loneliness in older people (not carers specifically) offer limited benefits. However, since only two of the studies in the review focused on carers of people with dementia, the results are unclear regarding this specific population.

Interventions which help carers develop coping abilities have been found to be some of the most useful (Milne et al. 1994). However, telephone, internet and computer based interventions aimed at promoting health, increasing physical activity and improving carer coping skills have had mixed results (Blom et al. 2015; Boots et al. 2014; Connell & Janevic, 2009; Godwin et al. 2013; Marziali & Garcia, 2011; McHugh et al. 2012; Tremont et al; 2008; Tremont et al. 2015). Educational training interventions based on developing problem solving and behaviour management skills have been shown to be effective at keeping carers supported, improving psychological health and reducing feelings of 'burden' (Andren & Elmsthal, 2008; Judge et al. 2013; Pusey & Richards, 2001; Selwood et al. 2007). Psychosocial interventions have also been shown to reduce carer burden and improve depression and anxiety (Gaugler et al. 2015; Schulz et al. 2014), however the long-term impact on carer mental health and coping ability is unclear (Phung et al. 2013). Some authors have emphasised how supportive interventions accessed early in the caring role by carers of people with dementia may help prepare them for possible difficulties ahead and reduce potentially negative effects on their health (Bauer et al. 2001; Dias et al. 2015). However, in general there is a lack of evidence for the effectiveness of psychosocial interventions for carers of people with dementia (Arksey, 2003) and also evidence that uptake of such services is low (Brodaty et al. 2005). The next section examines the potential reasons for low service use and the barriers which exist in accessing appropriate services.

2.5 Service use by carers of people with dementia

In middle and high income countries uptake of formal services by carers of people with dementia is often found to be low (Brodaty et al. 2005; McCabe et al. 1995). Reasons for non-use include carers feeling the services are not needed, that caring is their duty and responsibility, cost, lack of awareness, lack of availability, concerns over quality and resistance to accept outside help (Brodaty et al. 2005; Winslow, 2003). Despite this, evidence from the USA indicates many carers have unmet needs as a result of not accessing formal care and support services, these unmet needs are higher among minority ethnic carers and those with lower incomes or lower levels of educational attainment (Black et al. 2013).

Evidence suggests that black and minority ethnic (BME) carers residing in high income countries (in this case the USA) are less likely to access support services than White carers (Napoles et al. 2010). There have been attempts to explain this, ranging from distrust of mainstream support services (Dilworth-Anderson & Gibson, 2002), lack of cultural or religious appropriateness of services and a lack of awareness of service availability (Greenwood et al. 2015). In the USA, Gray et al. (2009) conducted a study looking at ethnic differences in dementia knowledge, attitudes and beliefs about Alzheimer's disease amongst female carers. Data were collected from 215 female carers surrounding what they thought about the risks of developing, causes and treatment of Alzheimer's disease. The results showed that Hispanic and Chinese carers were more likely to believe Alzheimer's disease was a normal part of ageing and could, for example, be diagnosed through a blood test. It was concluded that these beliefs contributed towards delayed help seeking by carers. In the UK, a study by the Institute for Research and Innovation in Social Services (IRISS, 2010) found that BME carers have particular difficulties in accessing services. As reported by Greenwood et al. (2015), low uptake of services was not always due to a lack of interest in using them, but a lack of awareness of appropriate services and a lack of information available in different languages. These studies show how carers of people with dementia from BME groups appear to be at a greater disadvantage and need more information about appropriate available support services.

Gender could also be a factor associated with low service uptake, as it has been reported that male carers tend to ask for help less often than female carers (Brown et al. 2007). This is supported by Coe and Neufeld (1999) in a study looking into male carers' experience of using and not engaging with formal support. It was only when they experienced a crisis in their caring role that they were more likely to ask for help. Understanding ways of reducing these barriers to accessing social support is vital, as it has been associated with improved long-term physical and mental health for carers of people with dementia (Goode et al. 1998). However, other evidence suggests male carers are more likely to make use of formal support services than female carers, with female carers more often turning to sources of informal support, such as family or friends (Laditka et al. 2001; Sanders, 2007). Further evidence suggests male spousal carers of people with dementia find it difficult in asking for help from friends or relatives, preferring to take on much of the caring tasks themselves (Harris, 1993).

With the varied evidence for the impact of the different types of support interventions for carers of people with dementia and numerous barriers to accessing these services, it is important to understand how English government policy has responded to the available evidence. The major policy document published in the England which directly mentions service development for carers of people with dementia is the English National Dementia Strategy (DoH, 2009).

2.6 The English National Dementia Strategy

This section describes the ways in which the English government uses the available evidence to inform the development of policies and strategies aimed at keeping carers supported. In 2009, England was one of the first countries in Europe to develop and publish a National Dementia Strategy (DoH, 2009). More recently, other European countries have published National Dementia Strategies, including Ireland, France, Italy, Denmark, and the Netherlands amongst others (Alzheimer Europe, 2015). A year after the publication of the English National Dementia Strategy in 2009, Scotland developed and published its own (Scottish Government, 2010). Wales has also recently developed a strategy for the development of services (Welsh Assembly Government, 2011).

In recognition of the difficulties caring for a person with dementia can present, the National Dementia Strategy (DoH, 2009) includes objectives intended to make improvements to dementia care in three main areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. These improvements relied on implementing 17 key objectives the strategy identified, not only for people with dementia, but also for their carers. The 17 objectives are listed in Table 2.

The strategy reported that carers of people with dementia are often frail, have high levels of mental illness and diminished quality of life. It pointed to the wider policy context relevant to carers as well as people with dementia which are: the National Carers' Strategy (DoH, 2008a), the National End of Life Care Strategy (DoH, 2008b) and Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care (HM Government, 2007). The vision of the National Dementia Strategy was to "...*enable people with dementia and their carers to live well with dementia*" (p. 21). One of the main purposes of the strategy was documented as:

> "...*provide a strategic quality framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia*" (p. 15).

Table 2. National Dementia Strategy (DoH, 2009) key objectives

Objective 1:	Public information campaign
Objective 2:	Good quality early diagnosis and intervention
Objective 3:	Good quality information

Objective 4:	A dementia adviser
Objective 5:	Peer support and learning networks
Objective 6:	Improved community personal support services
Objective 7:	Implementing the Carers Strategy
Objective 8:	Improving care in hospitals
Objective 9:	Improving intermediate care
Objective 10:	Housing and tele-care
Objective 11:	Improving care in care homes
Objective 12:	Improving end of life care
Objective 13:	Workforce competencies, development and training
Objective 14:	Joint local commissioning and world class commissioning
Objective 15:	Improved registration and inspection of care homes
Objective 16:	Dementia research
Objective 17:	National and local support for implementation

The strategy was developed in consultation with 50 stakeholder events across England and was attended by approximately 4000 people (DoH, 2009). Specific groups were also targeted to make sure people from minority groups could share their views, these included people with young onset dementia, people with learning disabilities, people from BME groups, people from rural or isolated communities, and older people in prisons. Approximately 600 responses were received, including from people with dementia and their carers, which fed into the development of the strategy.

Of the 17 key objectives, three are relevant to carers of people with dementia as well as those being cared for: Objective 2: Good-quality early diagnosis and intervention for all; Objective 5: Development of structured peer support and learning networks and Objective 7: Implementing the Carers' Strategy. Objective 2 underscored the importance of early diagnosis and interventions for people with dementia and their carers to help them to stay in their own homes for longer. This is partly due to carers being supported at an earlier stage if the person they are caring for is diagnosed sooner. It also argued that early intervention can have a positive effect on carers and reduce care home placements by up to a third. It is therefore imperative that early diagnosis for people with dementia is made so both they and their carers can gain maximum benefit from services, with the strategy describing how good-quality local services would be commissioned to increase the rate of diagnosis.

Objective 5 of the National Dementia Strategy (DoH, 2009) was the most relevant to the current research. It aimed to develop peer support networks to provide local support to people with dementia and their carers. It also suggested that the development of these services would enable people with dementia and their carers to take an active role in developing localised support. As part of the Carers' Strategy (HM Government, 2008) a Demonstrator Site project was setup to evaluate current best practice of different types of peer support to influence commissioning decisions. However, at the time the National Dementia Strategy (DoH, 2009) was published, it was expected that peer support would "*...provide practical and emotional support, reduce social isolation and promote self-care*" (p. 41). It was also stated that the voluntary sector would be supported in the development of peer support services by health and social care commissioners. The rationale for the development of peer support services for carers of people with dementia was the perceived benefits of talking to others in a similar situation to gain emotional support and advice. It noted that the challenges were first to understand which model of peer support worked best and then how to make them available locally for those who wished to access them. It is suggested that early diagnosis would increase the potential for the development of peer support networks. It also suggested that the development of peer support services can "*...empower people to make choices about what they want, and enable them to care for themselves*". (p. 42).

Objective 7 described carers as the most "*valuable resource for people with dementia*" (p. 49) and that making sure carers are fully support is important not only for their own health, but also for those they are caring for. It is noted how most carers want to care for the person with dementia at home for as long as possible, but there is often not enough assistance available to them. A year after the publication of the National Dementia Strategy (DoH, 2009), a revised, outcomes focused implementation plan was published (DoH, 2010). The aim of this update was to improve the speed of delivering key objectives, one of which was documented as "*good quality early diagnosis and intervention for all*" (p. 10).

The Prime Minister's Challenge on Dementia (DoH, 2012a) aimed to build on the National Dementia Strategy (DoH, 2009) by "*...improve radically the quality of life for people living with dementia, their families and carers by 2015*" (p. 4). It described how over the previous three years progress had been made at improving dementia services, but these had not been implemented quickly and were not sufficiently far reaching. It showed how the number of people using NHS memory services had increased by more than half between 2009 and 2011 and that more than 90 organisations had joined the Dementia Action Alliance (DAA) to work together to improve quality of life for people with dementia and their carers. The Prime Minister's Challenge on Dementia aimed to reach a new three year goal (2012 to 2015) by focusing on three key areas:

- Driving improvements in health and care
- Creating dementia friendly communities
- Better research

It was suggested that focusing on these key areas would not only benefit people with dementia and their carers, but also help relieve pressure on the NHS and social care services. Two aspects relating to these key commitments were previously documented in the National Dementia Strategy (DoH, 2009), indicating difficulty in implementing certain objectives. These include better diagnosis for people with dementia so they and their carers can gain earlier access to support services and promoting local information on dementia services. As part of promoting local information on dementia services, better support for carers was recognised as a target. It aimed to do this by requiring the NHS to work more closely with local community organisations and councils to provide a range of support services, including talking therapies. There was also the vision of creating 'dementia friendly communities' with the aim of helping people with dementia and their carers 'live well with dementia'.

Eight months after the publication of the Prime Minister's Challenge on Dementia (DoH, 2012a), a report on the initial progress of implementing the key objectives was released (DoH, 2012b). It showed how progress had been made on making dementia friendly communities which would help people with dementia and their carers to seek help, as it noted that 20 geographical areas in England have committed to becoming dementia friendly communities. Also the number of organisations which had joined the DAA had risen to 140. As part of the driving improvements in health and social care objective, progress had been made in providing more support to carers, in particular with peer support. This was achieved with the development of new Dementia Cafés, which it is suggested help to reduce social isolation for both carers and people with dementia. The hope is to help carers become less socially isolated and build dementia friendly communities.

A year after the initial Prime Minister's Challenge on Dementia (DoH, 2012a), an annual report of progress was published (DoH, 2013). Whilst continuing much of the progress described above, it also documented how carers are central to the English government's proposals for care and support. A priority was to identify carers or potential carers when a diagnosis of dementia is made and signpost them to appropriate support services. It was suggested this would enable them to look after their own health as well as have a life of their own outside caring. Among the next steps, it highlighted how by 2025 it wanted to demonstrate that faster diagnosis can have a beneficial impact on the quality of life of people with dementia and their carers.

2.7 Evaluations of strategies and interventions

Volunteer mentoring services (befriending, mentoring and peer support) were documented as an area for development for carers generally in the National Carers' Strategy (HM Government, 2008) and specifically for carers of people with dementia in the National Dementia Strategy (DoH, 2009). However, little evidence was presented in either the strategy for their effective use for this population. To this end, evaluations of these services were commissioned and the findings presented in the Evidence from the National Carers' Strategy Demonstrator Sites programme (Yeandle & Wigfield, 2011) and Healthbridge reports (Clarke et al. 2013).

2.7.1 Evidence from the National Carers' Strategy Demonstrator Sites programme

An evaluation in 2011 of the impact of the voluntary sector services set up as a result of the National Carers' Strategy (DoH, 2008a) investigated the effectiveness of 25 multi-agency demonstrator site projects, established to explore new ways of enhancing local and personalised support (Yeandle & Wigfield, 2011). Three of these sites developed befriending and peer support services, with another sign-posting carers onto similar services in the local area. These services were delivered by voluntary sector organisations, with the aim of involving carers with service delivery and assisting them to provide mutual support. The rationale behind developing befriending and peer support services was as a result of carers reporting a lack of social support and poor recognition of their needs (DoH, 1999; 2008a). It was hoped that it would increase carers' social networks to reduce social isolation. The voluntary sector organisations not only trained the volunteers, but also supported the organisations by carrying out Criminal Records Bureau (CRB) checks and offering a venue for service delivery. In all, data were collected from 5,050 carers. It showed carers were more likely to be older females, to have been caring for ten years or more, were caring for more than 50 hours per week and to be carers of people with dementia. After the 18 month trial period, it was found that those accessing befriending or peer support services reported they had better access to information, no longer felt isolated, found it easier to access leisure and employment opportunities, and that it gave them the feeling of 'having a life of their own'. Staff running the befriending and peer support services also highlighted the perceived positive outcomes for carers, including less isolation and better social support.

However, despite the high demand from carers for hospital based support services and carer assessments, demand for befriending and peer support services varied, with one site discontinuing its befriending service after an 18 months trial period because of lack of uptake. There were also challenges for staff delivering these new services. These included increased workload, their difficulty engaging with other services and concern that carers registered with them may be drawn away to other services, possibly making it difficult to attract future funding.

2.7.2 The Healthbridge report of peer support demonstrator sites

An evaluation of demonstrator sites was carried out looking into the impact of peer support for carers and people with dementia as a result of the National Dementia Strategy Implementation Plan (DoH, 2009). The aim of the Healthbridge evaluation study (Clarke et al. 2013) was to assess the numbers of carers and people with dementia accessing peer support services, the potential benefits of the support, and which models of peer support worked best and were helping to achieve the objectives of the National Dementia Strategy. In all, 40 demonstrator sites were established which developed either peer support or Dementia Adviser services. The aim was to provide people with dementia and their carers with wide ranging support in their local communities including information sharing, a chance to socialise and peer learning.

The evaluation also investigated the well-being of people with dementia and carers accessing the services using the Adult Social Care Outcomes Toolkit (ASCOT) (ONS, 2010) and the health related quality of life using the Dementia Quality of Life questionnaire (DEMqOL) (Banerjee et al. 2002). In total, 32 interviews with carers on their own who had received peer support were conducted. A further 17 joint interviews were conducted with both people with dementia and their carers. From the carers who took part in interviews, 82 completed the ASCOT questionnaire. The results showed that carers in the peer support demonstrator sites reported unmet needs in relation to social participation, accommodation, personal safety and security. However, a number of positive aspects to peer support were described by carers, including decreased isolation, increased confidence, feeling they were not alone, socialising in a safe environment and an opportunity to discuss emotional and practical difficulties. It also gave carers something to look forward to and provided a new focus and structure to their lives. However, it was also reported that not all carers found peer support useful and that this approach should be considered alongside other support services.

The Healthbridge report, like most service evaluations, aimed to describe the range and worth of a limited number of peer support services to improve service delivery. Therefore, research is needed not only to examine the effectiveness of peer support (along with befriending and mentoring) more generally, but also to investigate how and why it may or may not work. For example, the mechanisms by which peer supporters and carers form relationships, why it may be beneficial for some carers and not others, which aspects of volunteer mentoring carers find most useful and the impact of the various types of volunteer mentoring services. Further, research is needed to understand which models of volunteer mentoring offer the best outcomes for carers of people with dementia. The lack of clarity over which model to base future service development was highlighted in the Healthbridge report:

> "*There is no one definitive model on which to base future service development and attention is needed to local solutions to achieve sustainability within the local health and social care economy*" (Clarke, et al. 2013, p. 8).

However, as Yeandle and Wigfield (2011) suggest, effective carer support should always include a variety of services:

> "*No single type of carer support is best or offers a panacea for all carers or all caring situations. Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs*" (p. 131).

2.8 Conclusions

This chapter has discussed the available evidence for the experiences of carers of people with dementia and the interventions aimed at supporting them. The National Dementia Strategy (DoH, 2009) and an evaluation of the peer support services developed as a result of the strategy were also discussed. The evaluation showed some positive outcomes for carers, including decreased isolation and emotional support. However, the mechanisms by which peer support (and other types of volunteer mentoring) works, empirical evidence for their effectiveness and any potential impact on the volunteers delivering the interventions are missing. This research therefore aims to address these issues, but first background information to formal volunteering is presented in the next chapter.

3 Chapter Three: Volunteering and volunteer-led interventions

3.1 Introduction

This chapter provides contextual information on volunteering and volunteer-led interventions. It covers four main areas. Firstly, statistics on volunteering in the UK are presented. This is followed by an examination of the experiences of volunteers and impact of volunteering. Then an examination of the various types of volunteer mentoring services (befriending, mentoring and peer support) is presented. The chapter closes with the rationale for this research and the candidate theories framing the inquiry in attempting to explain the mechanisms and contexts by which volunteer mentoring succeeds or fails. These are Homophily Theory (Lazarsfeld & Merton, 1954) and Social Exchange Theory (SET-Emerson, 1976).

3.2 Volunteering in the UK

This research is concerned with formal volunteering facilitated by voluntary sector organisations, as opposed to informal volunteering which has been described as being "*...carried out individually outside of an organizational context*" (Lee & Brudney, 2012). The definition of volunteering which is used in this thesis is:

> "*...an activity that involves spending time, unpaid, doing something that aims to benefit the environment, individuals or groups other than (or in addition to) close relatives*" (Compact, 2005, p. 4).

As of 2013, there were 160,045 voluntary organisations in the UK, with a combined income of £40.5 billion (National Council for Voluntary Organisations (NCVO), 2015). The scale of these figures were matched by the number of people volunteering, with nearly three quarters (74%) of adults in England volunteering formally or informally in the 12 months between 2013 and 2014 (Cabinet Office, 2014). There has, however, been a reported decrease, with 27% of people reportedly volunteering formally once per month between 2013 and 2014, down from 29% who reported volunteering formally between 2012 and 2013. Similarly, a decrease in those who volunteered formally at least once per year has been observed, with 44% between 2012 and 2013, falling to 41% between 2013 and 2014.

There are a number of potential reason people may choose to volunteer, such as to 'feel good about themselves', giving something back to society or helping the transition from paid work into retirement (Davis Smith & Gay, 2005). However, not all parts of the UK population are equally engaged in volunteering. Females and those aged between 65 and 74 are most likely to engage in formal volunteering (Volunteering England, 2009). Further, it has been shown that people at risk of social exclusion, for example: BME groups; those with no qualifications and those who have a disability or long-term illness volunteer less than those not at risk of social exclusion (Low et al. 2007).

There is a long history of volunteerism in the UK. This will now be explored, with the focus on the post Second World War period through to the introduction of the Conservative Government's 'Big Society' manifesto (Conservative Party, 2010) and how it has helped to shape voluntary participation.

3.2.1 The post-war development of volunteering and government policy

3.2.2 Developments before 2009

There is an enduring tradition of volunteering and voluntary movements in the UK (Fairbairn, 1994; Hilton & McKay, 2011). Focusing on the post Second World War period, the 1960's saw a 'boom' in volunteering which coincided with increased pressure on the welfare state to provide services it could no longer maintain (Rochester et al. 2010). This involved volunteers providing services in an attempt to boost the quality and quantity of what was available to the public (Sheard, 1992), in particular efforts were made to recruit volunteers to the NHS. However, the view that the 1960's saw the start of a volunteering revolution is not shared by all. For example, Brewis (2013) argues that the volunteering movement was in existence prior to 1960, as the expansion of state welfare provision relied heavily on volunteers. Brewis (2013, p. 9) quotes from the 1955 book by Mary Morris to support this stance:

> "*...the use of voluntary workers in services for which the State is responsible is as old as the unpaid magistracy, and as new as the use of voluntary workers on regional boards and management committees for the administration of the nationalised hospitals*".

However, it has been suggested that the modern use of 'voluntary work' in health and social care services can be traced back to the Aves Committee report in 1969 (Rochester, 2013).

Despite the increase in the recognition of the importance of volunteers during the 1960's, it was only during the economic crash of the late 1970's and 1980's that the UK government started to actively promote volunteering as a way of reducing the burden on public services. For example, the National Good Neighbour Campaign was intended to encourage volunteers to look after disabled or elderly neighbours (Rochester et al. 2010).

In 1994 the Conservative government launched the 'Make a Difference Campaign' which coordinated jointly agreed volunteering policy for all four nations of the UK (Rochester et al. 2010). It has been described as the most ambitious attempt aimed at encouraging and supporting volunteering and viewed volunteering as a "*vehicle for participating and engaging in society, rather than as a vehicle for delivering public services*" (Rochester et al. 2010, p .90). This was later followed by legislation to help protect those who volunteer. For example, the Management of Health and Safety at Work Regulations Act (1999) compelled employers to carry out risk assessments on volunteers' activities for the first time.

Ten years after the Making a Difference Campaign, the Volunteering Compact Code of Good Practice (Compact, 2005) was published. It set out the agreement between the UK government and the voluntary sector to improve their working relationship to benefit each other. This code of practice also stated that it recognised the important contribution that volunteers made. It contained four fundamental principles which are: choice, diversity, mutual benefit and recognition.

More recently, the Safeguarding Vulnerable Groups Act (2006) sought to treat volunteers in the same way as paid employees when it came to working with children and vulnerable people. This meant that all who worked or volunteered with vulnerable people were required to undergo the Disclosure and Barring Service (DBS) checks. However, despite this and the numerous other policy updates and changes made by successive UK governments, volunteers are still not well protected by legislation. For example, the Data Protection Act (1998) does not apply to volunteers and the safety of their personal information.

In the next section, the UK Conservative Government's Big Society is explored. This section describes how this is not a new concept, and incorporates many ideals about increasing voluntary participation and improving community cohesion established by a cooperative called the Rochdale Society of Equitable Pioneers in 1844 (Fairbairn, 1994).

3.2.3 The Big Society concept and policy (2010 onwards)

Themes which would later develop into the concept of the Big Society were first discussed by David Cameron in 2005, for example, when he spoke about needing to "*mend a broken society*" (Woodhouse, 2013). Indeed, mending a broken society was central to the Conservative Party's manifesto in 2010.

The Conservative Party Manifesto (Conservative Party, 2010) starts by stating how "*the nations finances are mired in a massive debt*", that "*communities are shattered by crime and abuse*" and there "*...is a feeling of hopelessness*" among its people (p. vii). It goes on to suggest that the way out of the negative situation the country found itself in, was by building a stronger society and that the Big Society was the best way forward. The Conservative Party Manifesto (Conservative Party, 2010) sets out the ambition to build a Big Society by changing from a "*...big government that presumes to know best, to the Big Society that trusts in the people for ideas and innovation*" (p. viii). The overarching aim of the Big Society was to bring people and communities together by helping every adult become an active member of a neighbourhood group. The vision of the manifesto was to develop a society where people are coming together to help improve the lives of themselves and the communities in which they live. One way it suggested it could do this was by developing a public services reform programme which would:

> "*...enable social enterprises, charities and voluntary groups to play a leading role in delivering public services and tackling deep-rooted social problems*" (p. 37).

The reason the voluntary sector should play a major role in 'civic renewal' was perceived as being driven by "*Britain's long-standing and charitable tradition*" (p. 38). The manifesto highlighted how the Big Society was designed to empower communities and how this should encourage people to become part of neighbourhood groups to improve their local area. It reported that it would help fund these changes by enabling The Big Lottery Fund to focus on supporting social action through the voluntary and community sector. Further, The Mentoring and Befriending Foundation (2010, p. 3) suggested that mentoring and befriending should be central to the government's Big Society agenda as "*...they are fundamentally about active citizenship and community engagement.*"

The Public Administration Select Committee (PASC) published a report on what the Conservative Government's Big Society meant for Whitehall and if implementing the policy was on track to be successful (PASC, 2011). It outlined how the Big Society was not a new idea, and was linked to a cooperative movement established in Rochdale in 1844. The Big Society also had its roots in the theory of social capital, which has been described as:

> "*...we can think of social capital as the links, shared values and understandings in society that enable individuals and groups to trust each other and so work together*" (OECD, 2007, p. 102).

It has been argued that charities and voluntary groups are better able to engage hard to reach communities than the public or private sector (PASC, 2011). However, it was also noted that many voluntary organisations are too small to deliver some services adequately and may offer poor value for money when compared to those delivered by the state. Despite this, it was argued that due to their role in the community and local knowledge, voluntary organisations were best placed to deliver services of higher quality and lower cost. However, the PASC also presented evidence showing that considerable amounts of money had been drawn away from community and voluntary organisations, with some estimating it could be up to £5billion. This led to concerns that the reductions in public spending would undermine the Big Society project by stopping many voluntary organisations from participating (PASC, 2011).

Despite the challenges associated with the Big Society explored here, it has been a driving force for developing community engagement and implementing policies for improving volunteerism, which will now be explored.

3.2.4 Policy and legislation 2011 to 2015

Given the issue of recruiting and keeping volunteers (Bussell & Forbes, 2002), the Giving White Paper (Maud & Hurd, 2011) was developed and offered three main strands. Firstly fostering a culture of volunteerism, secondly removing centralised bureaucracy and finally enabling community empowerment. It set out goals to remove barriers to make volunteering more appealing which the voluntary sector had warned was on the decline. It argued that volunteering offered benefits for those giving as well as receiving and that "*...mutual support is at the core of a healthy, happy society*" (Maud & Hurd, 2011, p. 8). Despite the Giving Green Paper highlighting the UK as a giving and generous society (HM Government, 2010) it was suggested that the amount of giving had levelled off in recent years, which could make it harder for charities and community groups to continue the work they do. It was reported that volunteering was complex and not as rewarding as it should be. It also noted that the economic climate at the time could be a factor in the reduction in giving, and that subsequently encouraging more people to give would be a long-term project.

The Giving White Paper had three main aims (Maud & Hurd, 2011, p. 10):

1. *Make giving as easy as possible*
2. *Make giving as compelling as possible*
3. *Give better support to those that provide and manage opportunities to give – be they charities, community groups or others*

It suggested that large sums of money would be used to support volunteering over the coming years, including £40 million through the Social Action Fund and £80 million through the Community First programme, with the aim of increasing social action and removing barriers in neighbourhoods in England to promote volunteering.

Removing barriers was seen as an important aim in making it easier for people to give their time to volunteering. With bureaucracy and red tape emphasised as areas for improvement. It was shown that CRB checks were often a barrier to people volunteering and to organisations recruiting volunteers. To overcome this, they recommended continuously updating CRB checks and reducing the coverage of the Vetting and Barring Service for those who had contact with people with support needs. The Giving White Paper (Maud & Hurd, 2011) also emphasised how limiting volunteers' expenses was a barrier to some giving their time. Subsequently, the Approved Mileage Allowance Payments (AMAPs) was raised to 45 pence per mile. The removal of such barriers was expected to lead to an increase in people viewing volunteering as a more attractive or viable choice for them to give back to their community.

Along with removing barriers, The Giving White Paper suggested making it more compelling to give time through volunteering could be achieved by supporting approaches which use the 'power of reciprocity' as an incentive. Whilst noting there have always been incentives to volunteer, including learning new skills, meeting new people and satisfaction from helping others, new incentives needed exploring in order for people to give more. One way it was proposed to do this was by supporting the development of services which facilitate reciprocity. It is this 'sharing between people' that the UK government hopes will lead to stronger and more trusting communities. Projects which bring people together so they can help each other were of particular interest and for which funding would be made available.

The Giving White Paper further stated that the next steps were to '*...explore, develop and experiment with new models to increase giving by working with others across society*' (p. 49). One year later, the publication of The Giving White Paper: One Year On (HM Government, 2012b) provided an update of the progress made. Three key areas were highlighted as areas of achievement, including making it easier to give, making giving more compelling and supporting those who provide opportunities to others. The type of giving focused on here was largely about monetary donations as opposed to the giving time by volunteers. The future directions of the report are listed as: stimulating social action to help solve social challenges, continue to establish giving as a social norm and supporting the providers of opportunities. It was suggested in the future directions supporting the development of models which encourage reciprocity and recognising and valuing the work of volunteers. Recognising the work volunteers do was also explored in the Giving White Paper (Maud & Hurd, 2011), where it was highlighted that seeing people giving or volunteering and celebrating giving was a potential way of increasing participation in others. Next, an exploration of how UK policy has impacted upon volunteering since its publication is described.

3.2.5 The impact of policy on volunteering

> "*Our vision is of a society in which social action and reciprocity are the norm and where volunteering is encouraged, promoted and supported because it has the power to enhance quality, reduce inequality or improve outcomes in health, public health and social care*" (DoH, 2011, p. 3).

Despite the positivity of the above quote emphasising the importance of encouraging volunteering, some voluntary organisations are finding operating their services difficult. A study carried out by the Institute of Volunteering Research (Hutchison & Ockenden, 2008) explored the impact public policy has on volunteering in community-based organisations (CBOs). They conducted 24 semi-structured interviews with staff and trustees across eight organisations and held focus groups with volunteers in each organisation and found that volunteer recruitment was affected by levels of funding, with those able to secure new funding able to employ volunteer coordinators, better manage volunteers and contribute to a positive volunteering experience. Those with funding difficulties often had to cut back on refunding volunteers' expenses and training, which was described as "*damaging volunteers' moral*" (p. 30). However, it was shown that many participants did not feel public policy affected volunteer retention, with most volunteers leaving due to personal reasons. Those organisations which had lost funding felt they were neither managing nor supporting volunteers adequately. This largely related to cutting back on supervision, social events and not reimbursing volunteers' expenses. One-to-one and group support sessions for volunteers were becoming increasingly common due to funding requirements. Participants also noted that when money was available, they dedicated more time to training volunteers on topics they felt were necessary, such as health and safety. However, research findings documented later in this chapter highlight how large proportions of volunteers are unhappy with aspects of their role or the volunteering organisation (Low et al. 2007; Ross et al. 1999). It suggests how funding cutbacks could potentially impact on the recruitment and retention of volunteers.

One area where CBO staff had noticed an impact of policy change was an increase in the numbers of volunteers using it as a route back into employment, possibly as a result of the government's drive to move unemployed people into paid work. Some viewed volunteering as a training placement which had increased the amount of time organisations were spending on training and supporting them. Other participants also felt that policy trends for the professionalisation of the community and voluntary sectors meant that more was being asked of them. Staff of CBOs had noticed an increase in paperwork due to policy changes, such as risk assessments and CRB checks, which in turn reduced the amount of time they could spend supporting volunteers. Funding problems and staff shortages were also found to increase the responsibility and amount of work expected of volunteers, which they were not always happy to do as they were unpaid.

With the push from central government to increase formal volunteering as a way of bringing people together and improving social cohesion, it is necessary to understand what evidence exists for the benefits or negatives of volunteering. Therefore, the impact of volunteering and experiences of volunteers are explored next.

3.3 Experiences and impact of volunteering

3.3.1 Impact on physical and mental health

There is evidence to suggest that volunteers benefit from volunteering, for example: reduced depression (Kahana et al. 2013; Lum & Lightfoot, 2005; Musick & Wilson, 2003); improved physical health (Borgonvoni, 2008; Burr et al. 2013; Casiday et al. 2008; Riegel & Carlson, 2004; Peardon et al. 2010; Tang, 2009); improved quality of life (Cattan et al. 2011) and reduced mortality risk (Harris & Thoresen, 2005). However, other evidence suggests that primarily older adults aged over 65 are likely to benefit long-term from volunteering (Kim & Pai, 2010) and the evidence for the positive impact on physical health is mixed (Lum & Lightfoot, 2005; Piliavin & Siegl, 2007).

Adding to the evidence for the potential benefits of volunteering, Piliavin and Siegl (2007) demonstrated that it is associated with psychological well-being and that volunteering was also likely to lead people to feel good about themselves. Furthermore, it was also shown that those who were less well socially integrated benefitted most from volunteering. An explanation for this finding was described by Prouteau and Wolff (2008) who focused on understanding the relational motives for the reasons why people choose to volunteer. They found that volunteers reported wanting to make friends and meet other people by increasing their social circle through volunteer work.

There are a number of theories which aim to explain less obvious motivations for the reasons why people choose to volunteer in later life. For example, Activity Theory (Lemon et al. 1972) argues that people may choose to volunteer due to a loss of role and decreased social activity, perhaps after bereavement. However, it was later suggested by Chambre (1984) that Continuity Theory might be a better option for understanding the reasons why people choose to volunteer in later life, as it was found that people were continuing behaviour patterns established earlier in life. Many volunteers also gain a sense of satisfaction and social engagement from their role, this is explored in the next section.

3.3.2 Satisfaction and social engagement

Fyvie-Gauld and de Podesta (2007) reported that people were most likely to volunteer if the times available to volunteer were convenient and if they found it rewarding. People were also more likely to continue volunteering if the volunteer coordinator was readily available to them, either over the telephone or in person. The volunteer coordinator and the assistance offered to volunteers could be seen by potential volunteers as a way of gaining the psychological support they need for themselves. Musick and Wilson (2003) found evidence to suggest that for those over the age of 65 volunteering could help reduce levels of depression as the volunteers have additional access to social and psychological resources.

This suggests that the volunteer coordinator could assist in maintaining the well-being of the volunteers and retaining them long-term by providing them with additional support.

Low et al. (2007) reported a survey which showed 97% of volunteers gain satisfaction from seeing the positive results of their volunteering, with 98% reporting enjoyment as a central benefit of volunteering. Satisfaction is an important outcome for volunteers and is likely to result in them choosing to give time to a cause they see as personally meaningful (Tang et al. 2009). However, there is evidence to suggest volunteers report less satisfaction from their role than paid employees (Ferrari et al. 2007), possibly due to the lack of training in how to deal with challenging situations.

Evidence suggests that retired older people experience satisfaction with formal volunteering and are more likely to be satisfied in retirement than those who are not engaged in volunteering or other social activities (Butrica & Schaner, 2005). Further, increases in self-esteem (Narushima, 2005; Primavera, 1999) and self-confidence (Thoits & Hewitt, 2001) have been reported benefits for those who regularly engage in volunteering activities. Another reported benefit from volunteering is social interaction, with the importance of meeting people and making new friends an important outcome for volunteers (Low et al. 2007; Lum & Lightfoot, 2005; Piliavin & Seigl, 2007). The importance of making friends through volunteering was also described by Prouteau and Wolff (2008), with it being second only to wanting to help others as a reason for deciding to volunteer.

It has been shown here that volunteering can be seen as beneficial for people who are socially isolated allowing them to make new friends, by increasing positive feelings about themselves and also that people are likely to volunteer based upon flexibility of the time commitment they are required to give. Therefore, the experiences of volunteers who deliver the interventions need to be clearly understood in order for them to gain the maximum benefit from the experience. It is also important to ensure they are being fully supported to carry out their voluntary work with as much flexibility as possible. Despite the numerous reported positive aspects to volunteering, there are also negative impacts on volunteers.

3.3.3 Negative aspects of volunteering on volunteers

Whilst it has been shown there are many positive aspects to formal volunteering, there are also a number of potential negatives and drawbacks which have been reported. In a national

UK survey of volunteering, Low et al. (2007) found that more than a third of volunteers felt their volunteering could be better organised, just under a third suggested there was too much bureaucracy and a quarter felt there was an obligation to stay since there was no one else to fill their role. Stress can also be a detractor for volunteers. For example, it has been shown that volunteers are more likely to leave their role if they experience difficulties with the person they are helping, 'emotional overload' or role ambiguity (Ross et al. 1999).

Evidence presented by Krause et al. (1992) suggests formal volunteering may fail to have significant beneficial impact on volunteers' psychological well-being. This can occur if the volunteer cannot see a positive impact on the volunteer recipient or if there is no reciprocity in volunteering. Krause et al. (1992) emphasised how older adults are likely to adhere strongly to the concept of reciprocity in social relationships in an attempt to maintain a balance of exchange in their social networks. Overall, it was explained how lack of observable positive impact or reciprocity through volunteering are likely to negatively affect volunteer retention. The importance of seeing evidence of the positive impact resulting from volunteering is also shared by Matsuba et al (2007), who suggested:

> "(volunteers who) *feel that they will make important contributions to the welfare of others, are more committed to volunteering than are those who do not share these characteristics*" (p. 901).

Other potential negatives of volunteering and reason for poor volunteer retention have been suggested as poor training and support from service providers (Ross et al. 1999), lack of recognition or rewards for their efforts (Wilson, 2000) and a feeling from potential volunteers of being 'tied down', leading to a barrier in participation (Warburton et al. 2001). Additionally, Dean and Goodlad (1998) reported that six in ten befriending services in the UK have difficulty in attracting adequate numbers of volunteers and a third find volunteer turnover problematic.

3.3.4 The role of former carers in volunteering

Little is understood about the experiences of former carers, particularly regarding the emotional and social losses which can occur once caring ends (Cronin et al. 2015). There is some evidence to suggest that whilst the end of the caring journey can result in relief of some stress or burden, it can also result in many years of adjustment involving grief or depression (Carers UK, 2004). This adjustment has been described as a 'post-caring void' (Larkin, 2009) and can encompass feelings of grief and loss. However, in moving on from grief former carers often try 'constructing a life post-caring'. Identifying ways in which former carers are able to redevelop a social circle and gain emotional support could have important implications for current carers. However, much of the available literature focuses on what former carer peer supporters can offer current carers, without any in-depth consideration on the impact (positive or negative) on former carers (e.g., Stewart et al. 1998). Nevertheless, there is evidence to suggest that peer supporters in general gain improvements in confidence, self-awareness, self-esteem and depression from their role in helping others (Greenwood et al. 2013; Schwartz & Sendor, 1999). Further still, former carers of people with dementia have been shown to be valuable as 'peer educators' for current carers, working alongside professional health care workers to provide support (Sharpe et al. 1996). Given that previous research in this chapter (Musick & Wilson, 2003) highlighted how volunteering could reduce depression and increase access to social resources, understanding the impact of volunteering on former carers is therefore an important area for exploration.

This section has explored the impact and experiences of volunteer mentoring on volunteers. Next, an examination of how volunteer mentoring works and the potential impact they have on those accessing the services is presented.

3.4 Volunteer mentoring services

The different types of volunteer mentoring (befriending, mentoring and peer support) are used across a wide range of services for people with varying needs. Although this research uses volunteer mentoring as an overall term when describing them collectively, the similarities and differences between them will be explored separately. This section discusses each in turn, with definitions of each, followed by evidence for their impact and effectiveness.

3.4.1 Befriending

3.4.1.1 Definition

Befriending is a formal process usually initiated by voluntary or other third sector organisations to bring two people together who may otherwise not have met (Dean & Goodlad, 1998). It has been described as the development of a friend-like relationship, which is overseen by a providing body (MacDonald & Greggans, 2010). The definition of befriending which will be used in this research comes from Dean and Goodlad (1998), who defined befriending as:

> "*A relationship between two or more individuals which is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit. Ideally the relationship is non-judgemental, mutual, purposeful, and there is a commitment over time*" (p. 5).

McGowan et al. (2009) suggested that befriending may be a route to a better quality of life for many people:

> "*....a befriending relationship may be the beginning of a route back to gaining the increased confidence and self-esteem necessary to enable the individual to recreate and develop their own unique social network, improve their psychological well-being and enrich their quality of life*" (p. 624).

The importance of developing befriending services for carers has been recognised by the English government as an area for development, in order to "*avoid isolation and loss of connectivity with family, friends and place*" (HM Government, 2010a, p. 47).

3.4.1.2 ***Potential impact of befriending interventions***

There is evidence to suggest that befriending can be effective at reducing depression and social isolation and can be a source of practical support for people from a variety of populations and with varying needs (Dean & Goodlad, 1998; Harris et al. 1999; Harris, 2006; Masi et al. 2011; McBriar et al. 2001; Milne et al. 2006; Mulvihill, 2011). Further, befriending has been shown to be as effective as cognitive behavioural therapy (CBT) in reducing initial symptoms of schizophrenia (Sensky et al. 2000), but patients need to be well enough to successfully engage with the befriending intervention for it to be effective (Samarasekera et al. 2007). The effects of befriending interventions on socially isolated older people are unclear (Cattan et al. 2005). However, none of the studies in the systematic review by Cattan at al. (2005) focused on carers. This was later examined by Mead et al. (2010) who conducted a systematic review and meta-analysis on the effects of befriending on carer depression. Overall, 24 studies were included in the meta-analysis, but only one focused on carers of people with dementia (Charlesworth, et al. 2008). The results showed that befriending had a modest effect on depressive symptoms in the short and long-term. It was suggested that using depression as the primary outcome measure may have led to publication bias due to studies being more likely to report positive results. Further, it was argued that depression may not be the most appropriate outcome measure for befriending and its most important benefits could have been missed.

There is evidence to suggest befriending offers the befriendee (the person being befriended) benefits, by giving the opportunity to engage in social activities (Heslop, 2005). It can also build confidence in social situations (Bradshaw & Haddock, 1998). However, research has shown potential negatives for both volunteers and befriendees. For example, Cox et al. (1991) in an evaluation of a befriending service for young mothers with depression, found that there was a high failure rate of befriending relationships. Approximately one third of young mothers did not sustain involvement with befriending, with those volunteers who had more experiential experiences (in this case a lived experience of mental ill health) and had completed more training prior to matching were more likely to form lasting befriending relationships with the befriendee. This was also reported by Ferguson (1981) who showed how matching befrienders to people with enduring mental illness on the basis of common interests had a positive impact on the development of befriending relationships.

Developing a successful befriending relationship between two people has been described as needing a balance of power whereby mutual friendships develop, as opposed to simply giving and receiving a service. For example, Lester et al. (2012) describe how unsuccessful befriending relationships were often not reciprocal, where the befriender talked 'too much' and did not listen effectively. In contrast to previous research found (Suitor et al. 1995), experiential similarity (in this case ill health, bereavement or loneliness) was not found to be important factors in developing successful befriending relationships. However, in general having a befriender who was friendly and a good listener were important to the development of trust, but matching by services based on commonalities were described as unnecessary.

The importance of commonalities and 'matching' for the success of befriending relationships was shown by Peardon et al. (2010) in patients with heart failure. Here befrienders went through thorough training and matching processes to maximise the chances that the first meeting with the befriendee was a positive one. All 50 patients who received help from a volunteer befriender described befriending as worthwhile and that they would recommend it to other heart failure patients. It has also been shown how befrienders and befriendees value a shared empathy and mutuality, but that there are challenges around establishing an emphatic relationship based on trust and reciprocity (Mitchell & Pistrang, 2011). Where trust and reciprocity have not been formed, befriending relationships are often found to be unsuccessful (Andrews et al. 2003).

With reference to the above, from this point on successful volunteer mentoring will refer to the extent carer and volunteer relationships are reciprocal and mutually beneficial.

3.4.2 Peer support

3.4.2.1 Definition

The definition of peer support which is used in this thesis was taken from Sherman et al. (2004, p. 140), who described a peer supporter as:

> "...*someone who has faced the same significant challenges as the support recipient,* (and) *serves as a mentor to that individual*".

Whilst there is an overlap between mentoring and peer support, it is important to highlight that a mentor does not necessarily have the same previous experience as that of the mentee, whereas this is essential in peer support relationships. For example, Keyes et al. (2014) reported how exchanging information (such as advice and coping strategies) with similar others was a key aspect of peer support.

3.4.2.2 Potential impact of peer support interventions

Peer support, both face to-face-and over the telephone, has been shown to offer benefits to various populations with varying needs, for example reducing depression (Dennis, et al. 2009; Pfeiffer et al. 2011; Winter & Gitlin, 2007), improving coping ability (Bjorck & Klewicki, 1997) and reducing the chance of relapse in those with severe mental illnesses (Sledge et al. 2011). The positive impact of peer support was also reported by Stewart et al. (2006) who conducted a study into telephone peer support for carers of people with long-term health conditions. The qualitative findings from this study of 66 participants showed that carers had increased coping skills and caregiving competence, decreased feelings of burden and loneliness. It was concluded that peer supporters' experiential knowledge and the benefits to carers' social networks were key factors for its success. Further, peer support has been shown to have a positive impact on carers' mental health by offering the opportunity to develop empathic relationships with someone who has experienced, and successfully been through, similar life events (Veith et al. 2006).

The importance of experiential similarity and passing on knowledge by peer supporters was also demonstrated by Riegel and Carlson (2004), who found that peer support resulted in significantly improved heart failure self-care than those not receiving peer support. However, the benefits associated with peer support may not apply to all health conditions. For example, Uccelli et al. (2004) reported that peer support groups do not provide improvements in quality of life or depression scores for those with multiple sclerosis. Further, Davidson et al. (2006) suggested that although peer support (in this case for those with severe mental illnesses) was becoming increasingly popular, little is known about how the personal experiences of the peer supporter (in terms of experiential similarity) facilitate the engagement and recovery of those receiving the intervention. Further still, although some recipients of peer support report high levels of satisfaction, evidence for its impact on psychosocial outcomes for those with cancer or enduring mental illnesses is lacking (Hoey et al. 2008; Lloyd-Evans et al. 2014).

For carers of people with dementia, telephone peer support has been shown to offer beneficial outcomes, including emotional support, improved perceived social support and increased caring knowledge and skills (Bank et al. 2006; Goodman & Pynoos, 1990). Technology provided support groups (e.g. telephone, internet forums or video conferencing) have been shown to reduce burden and improve social networks in a similar way face-to-face support has for carers of people with dementia (Lee, 2015). In contrast, other evidence suggests computerised interventions which have elements of peer support: including online forums, message boards, email contact and video conferencing have only a moderate effect on carer depression, anxiety and stress (Godwin et al. 2013; Powell et al. 2008).

3.4.3 Mentoring

3.4.3.1 Definition

The following definition of mentoring suggests it is often provided to those who have insufficient information and who may need guidance for a variety of reasons. For example:

> "*...someone who has advanced experience and knowledge and who is committed to assisting, guiding and providing support in your career, personal and professional development*" Fowler and O'Gorman (2005, p. 52).

Whilst Fowler and O'Gorman's (2005) study was primarily concerned with mentoring in the work place, this definition does show the ways in which a mentor in general will be a more experienced person imparting their knowledge onto another, less experienced person. A less specific definition describes mentoring as:

> "*...advice and support given to those who need it by influential people who wish to be helpful*" (Haring, 1999, p. 8).

The variability in the type of mentoring services available was examined by Clayden and Stein (2005) who distinguished between 'hard' and 'soft' outcomes:

> "*...the purpose of mentoring services can be defined on a continuum. This may begin with 'instrumental' or 'engagement mentoring' linked to 'hard' outcomes, such as employment, education or training, or reducing offending behaviour, and continue to more 'expressive' mentoring linked to 'soft' outcomes, such as self-esteem and personal development*" (Clayden & Stein, 2005, p. 1).

Highlighting the confusion and overlap between befriending and mentoring, some mentoring interventions in the USA would often be described as befriending services in the UK (MacDonald & Greggans, 2010). However, although the initial facilitating of mentoring and peer support relationships can be similar, for example, with the use of matching, it has been suggested that peer support offers a 'two-way' exchange, whereas mentoring is a largely 'one-way' flow of passing on information from mentor to mentee (Kram & Isabella, 1985).

3.4.3.2 ***Potential impact of mentoring interventions***

In order to identify the mentoring processes which result in positive outcomes for student nurses, Eller et al. (2014) described eight themes which they described as key components to an effective mentoring relationship:

1. open communication and accessibility
2. goals and challenges
3. passion and inspiration
4. caring personal relationship
5. mutual respect and trust
6. exchange of knowledge
7. independence and collaboration
8. role modelling

Despite many of the above goals of mentoring being similar to those of befriending and peer support, there are differences. For example, Cox (2005) argued that matching mentors and mentees is much less important than the mentors' background, with training mentors in how to build rapports and empathy most important to successfully develop mentoring relationships. Further, Cox (2005) suggested recruiting volunteers with a broad educational and employment background, along with adequate life experience was needed most in understanding the process of the development of successful mentoring relationships and that matching criteria were unnecessary. Highlighting the diversity of opinion surrounding the importance of matching, Clayden and Stein (2005) suggested that matching was crucial to the successful creation of mentoring relationships.

3.4.4 Summary of the gaps in knowledge surrounding volunteer mentoring

The evidence of the benefits of volunteering described above give weight to the English government's policies of increasing participation in formal volunteering. This, coupled with increasing the number of volunteer mentoring services for carers of people with dementia (outlined in Chapter Two: The National Dementia Strategy and the Healthbridge Report), means it is essential to understand what evidence exists for the potential impact of these services on the people accessing them and the volunteers delivering them.

3.5 Explanatory theories

The theoretical perspectives which will be used to explore and explain the findings of this research are Homophily Theory and Social Exchange Theory (SET). Homophily Theory has been chosen by drawing on evidence regarding the importance of experiential similarity, SET has been chosen in response to the evidence suggesting that volunteers are more likely to continue volunteering if the relationships are mutually beneficial. These theoretical perspectives will now be described in greater depth.

3.5.1 Experiential similarity in the development of relationships

There is evidence to suggest carer and volunteer relationships develop faster and are longer lasting if matching for similarity has taken place beforehand (Andrews et al. 2003). This can be explained by Homophily Theory, which suggests that people are more likely to interact and engage in supportive relationships with others who are similar to themselves on important social dimensions (Suitor et al. 1995). There is also evidence to suggest that ties between those who share little in common are more likely to dissolve than those who share similarities (McPherson et al. 2001). Support for matching volunteers and support recipients has been shown with befriending (Dean & Goodlad, 1998), with matching on issues such as shared interests important to the success of befriending relationships. Further, Pillemer and Suitor (2002) highlight the importance of 'similar associates' when undergoing stressful life events, such as recently becoming a carer. In particular, they suggested experiential similarity was highly important where the 'associates' have also been through the same experiences. The importance of experiential similarity was explained by Thoits (1986), who argued that it was the most crucial aspect to the support process as it helped the development of empathic understanding. Similarly, Veith et al. (2006) found that peer mentoring provided the opportunity for the formation of empathic relationships to a 'similar other'. They suggested that a peer mentor who had experienced and successfully been through similar life events could help the person being mentored adjust to their new situation.

This thesis utilises the theoretical basis of Homophily Theory developed by Suitor et al. (1995) which suggests experiential similarity is likely to be more indicative of who is likely to be a source of social support than structural similarity. The origins of Homophily Theory will now be examined.

3.5.1.1 ***Homophily Theory***

Homophily Theory assumes that those who are similar to each other on important social dimensions are more likely to develop mutually supportive relationships (Bell, 1981; Feld, 1982; Marsden, 1988). McPherson et al. (2001) suggest that people who are similar often build stronger connections to each other and that contact between people with similar social attributes occurs at a higher rate than those who are dissimilar. As Kossinets and Watts (2009) argued:

> "*Friends, spouses, romantic partners, co-workers, colleagues, and other professional and recreational associates all tend to be more similar to each other than randomly chosen members of the same population with respect to a variety of dimensions, including race, age, gender, socioeconomic status, and education*" (p. 406).

People who are similar on one or more of such attributes are also more likely to share a more trusting relationship, as Burt (1992, p. 64) suggested:

> "*...the formation of close, trusting relationships seems to be that a person more like me is less likely to betray me*".

Whilst homophily is largely concerned with the attraction of similar individuals, there is evidence to suggest choice homophily (McPherson & Smith-Lovin, 1987) can occur due to the avoidance of others. For example, Schaefer et al. (2011) highlighted how similarity of depression levels among friends could be due to the avoidance and withdrawal of non-depressed people. McPherson and Smith-Lovin (1987) also suggested there was induced homophily, whereby people form ties with similar attributes because they are disproportionately surrounded by others like themselves.

Investigating carers of people with dementia, Suitor et al. (1995) explored which types of homophily, structural or experiential, are most likely to be important in facilitating and maintaining supportive relationships. The authors hypothesised that experiential similarity would be the overriding factor to the development of supportive relationships, with structural similarity having a less important role, but still possibly influencing patterns of support. The findings showed experiential similarity was the only variable which was consistently related to the provision of emotional support in social networks. It was also shown that people in carers' networks who had experiential similarity were less likely to be sources of interpersonal stress, when compared to those without prior caring experience. It was argued that experiential similarity created a shared empathy and understanding whereby carers could more easily share difficulties they were experiencing. It was also shown that gender, but not age was a predictor of emotional support. Overall it was concluded that experiential similarity is more important than structural similarity in the development of supportive relationships.

Despite the perceived importance of experiential similarity for carers of people with dementia in forming social ties, there is also evidence to suggest that volunteers seek reciprocity when forming relationships. This will be explored next, with attention given to how SET can potentially explain why some volunteer mentoring relationships are stronger than others.

3.5.2 Reciprocity and mutual gain

Volunteering has been generally regarded as a selfless act which benefits society (Putnam, 2000). However, there is evidence to suggest that reciprocity or the prospect of mutual gain influence decisions to volunteer (Krause et al. 1992). Further, research has shown that reciprocal exchange builds trust and commitment (Molm et al. 2000; Palo Stoller, 1985). Mutuality and reciprocity have been described as:

> "*Mutuality and reciprocity refers to arrangements designed to enable those involved to give and receive support, compared to those where one individual or group of people is intended to be the recipient(s) of services/support provided by another person or organisation. These arrangements may be formal or informal, and /or highly organised or fairly fluid*" (Bowers et al. 2011, p. 4).

Manatschal and Freitag (2014) suggested that reciprocity and volunteering are connected, in that voluntary engagement depends on individual reciprocal attitudes. For example, they argued those who have received help in the past may want to repay this help in the form of altruistic reciprocity. Strategic reciprocity was also highlighted as a reason to volunteer, in that helping someone else may result in receiving help in the future (Plickert et al. 2007). However, Bowers et al. (2011) argued older people generally have low levels of awareness about services based on mutual support, despite there being a great deal of interest in the concept of taking part in mutually supportive activities in the community.

3.5.2.1 Social Exchange Theory (SET)

The basis of SET is that people interact with others on the expectation of receiving something in return and that this is not limited to the exchange of material goods (Homans, 1958). This was defined by Cropanzano and Mitchell (2005, p. 890) as:

> "*Social exchange comprises actions contingent on the rewarding reactions of others, which over time provide for mutually and rewarding transactions and relationships*".

The idea of relationships containing social exchanges and reciprocity was first reported by Homans (1958), who suggested that people who are giving to others also try to gain from them, whilst at the same time those who are receiving feel the need to give back. Homans goes on to say that exchanges tend to even out so all involved have gained equally:

> "*This process of influence tends to work out at equilibrium to a balance in the exchanges*" (p. 606).

Emerson (1962) adds to this, suggesting that mutual dependence and reciprocity are what binds people together in social relationships. Blau (1964) also highlighted that exchanges are mutually beneficial for all people involved. "*Social exchange as here conceived is limited to actions that are contingent on rewarding reactions from others*" (p. 6). Further, the aspect of mutual sharing among people in order to benefit from each other was described by Burger et al. (2009), with the idea of the 'norm of reciprocity'. This is where people who are receiving support and assistance feel the need to give something back or repay it. If the person receiving the help or assistance is able to reciprocate, a more trusting and mutually beneficial relationship can form over time (Cropanzano & Mitchell, 2005). Further still, there is evidence to suggest that interventions that emphasise or encourage reciprocal or mutual exchanges of support report better outcomes for the support recipients (Hogan et al. 2002).

Chibucos et al. (2005) argued there are three key assumptions of human interaction with regards to SET. Firstly, individuals engage in calculations of potential costs and benefits in social interactions. Second, in order to meet an individual's needs, they will seek to 'maximise the profits' from interactions:

> "*The theory's fundamental principle is that humans in social situations choose behaviors that maximize their likelihood of meeting self-interests in those situations*" (p. 137).

Thirdly, people fall into patterns of social interactions with others producing 'payoffs' in terms of meeting their needs. Subsequently, it was suggested that people will engage with others where the benefits of the interactions outweigh the 'costs'. The idea of costs and benefits in social interactions was described by Emerson (1976, p. 336):

> "*...the exchange approach in sociology might be described, for simplicity, as the economic analysis of noneconomic situations*".

3.6 Conclusions

This chapter has set the contextual background on volunteerism in England before focusing on the evidence base concerning the impact of volunteer mentoring services. Whilst there is some evidence for the effective use of volunteer mentoring in a number of different populations, their use and impact on carers of people with dementia is unclear, despite being promoted in the English National Dementia Strategy (DoH, 2009). From the general evidence on volunteer mentor services, Homophily Theory and SET are candidate explanatory theories for the success or failure of such services and frame this inquiry.

This research therefore addresses the gap in the literature. Firstly, a systematic literature review (Chapter Four) was undertaken in order to identify the available evidence of the impact of these services specifically on carers of people with dementia and the volunteers who deliver the interventions. This was followed by a survey of services (Chapter Five) which investigated the similarities and differences in how volunteer mentoring services were operating. Together, Chapters Four and Five comprise Phase One of this research.

4 Chapter Four: Systematic literature review

4.1 Introduction

This chapter marks the beginning of Phase One of this research and reports a systematic literature review. It investigated the available empirical evidence for the impact of volunteer mentoring on carers of people with dementia and on volunteer mentors. Chapter Two demonstrated the need to investigate ways of supporting carers of people with dementia, given the predicted increase in diagnoses of dementia over the coming decades (Knapp et al. 2007; Prince et al. 2015). This chapter also explored potential ways to support carers, in particular through varying forms of social support. It described how there was a large body of research, in particular surrounding befriending and peer support, for carers and those with varying conditions. However, given the evidence in Chapter Three regarding the English government's policy to increase volunteer mentoring services for carers of people with dementia, it was essential to investigate the impact on carers and the volunteers delivering the interventions. Underpinned by the researcher's worldview, a pragmatic approach to identifying and including available evidence was taken. Studies were not excluded based on the methods used and the findings of this review shaped the research questions for a survey study (Chapter Five). A publication resulting from this chapter (Smith & Greenwood 2014a) is available in Appendix 1.

4.2 The importance of the review

With volunteer mentoring services for carers of people with dementia likely to increase and evidence for the effective use of volunteer mentoring services in other populations (Dean & Goodlad, 1998; Mead et al. 2010; Veith et al. 2006), it is important to understand what evidence exists for their effective use in this population. It is also important to identify any benefits for the volunteers who deliver the interventions, as previous research has reported potential benefits for volunteers who engage in volunteer mentoring services (Casiday et al. 2008). Investigating the effectiveness of volunteer mentoring services in both carers of people with dementia and volunteer mentors, should lead to a greater understanding of the benefits and may identify which type of volunteer mentoring might be most beneficial to both groups, if any.

This review went further than those previously reported (e.g. Mead et al. 2010) as it was both more inclusive of the types of volunteer mentoring service investigated (befriending, mentoring and peer support) and was also focused on carers of people with dementia. Further, it attempted to increase understanding of what underpins a successful volunteer mentor and carer relationship. Another reason for conducting this systematic review was to build on the findings of previous reviews which investigated various types of services accessed by carers and the outcomes they provided, but often lacked systematic and comprehensive review methods (Beeson, 2003; Etters et al. 2008). Developing a robust and comprehensive literature search which includes studies of quantitative, qualitative and mixed methods methodologies enabled more reliable and comprehensive conclusions to be drawn about service use and the outcomes they offer carers of people with dementia and volunteer mentors. The findings of this review were used in developing the later research questions of the thesis.

In addition, this review was not only limited to the impact on carers but also incorporated the impact on volunteers of volunteer mentoring. To provide more focused answers, this review was also limited specifically to volunteers as opposed to professionals delivering a volunteer mentoring intervention for carers of people with dementia.

4.3 Aims and research questions

The aims of this systematic review were to synthesise and appraise the empirical evidence for the impact of different types of volunteer mentoring services on both carers of people with dementia and on volunteers. It helped to identify the current level of knowledge and gaps in the literature in this area.

The specific research questions are:

1. What are the differences and similarities between the different types of volunteer mentoring services in how they operate? For example, frequency of sessions and length of contact.
2. What outcomes are investigated for carers and volunteers?
3. What is the evidence for the impact these interventions have on carers and volunteer mentors?
4. What is important for successful volunteer mentor and carer relationships?

The specific question formation was addressed using the Patient, Intervention, Comparison and Outcome (PICO) process as documented by the CRD (2008) and is presented in Table 3.

Table 3. Question formulation using the PICO process

Patients/Participants	Interventions	Comparisons	Outcomes
Carers of people with dementia and volunteers.	Befriending, mentoring or peer support services.	Usual care (if available) compared with the interventions.	For example: impact on mental health, social isolation, self-esteem, quality of life and formation of relationships; for both carers and volunteers.

4.4 Methods

The following section describes the review selection criteria, search strategies, quality assessment, data extraction and management, data synthesis and the changes made to the methods after the completion of the review protocol (available in Appendix 2). This review was reported in accordance to the Centre for Reviews and Dissemination guidance, for undertaking reviews in health care (CRD, 2008).

4.4.1 Study selection criteria

4.4.1.1 Types of studies

Research studies which used quantitative, qualitative and mixed methods approaches were eligible for inclusion.

4.4.1.2 Inclusion criteria

- Studies which identified the person being cared for as having dementia
- One-to-one volunteer support
- Interventions delivered by volunteers
- Studies which involved face-to-face, telephone or internet support
- Interventions could take place in any location, such as a carers' home, community based facilities or other appropriate setting
- English language articles

4.4.1.3 Exclusion criteria

- Studies where it was not possible to identify if any main effects were due to volunteer mentoring
- Studies which included carers of people with other conditions where carers of people with dementia make up less than 50% of the total number of participants
- Studies which involved support not clearly identified as befriending, mentoring or peer support
- Review articles
- Conference papers

4.4.2 Search strategy

A combination of different resources including both published and grey literature was searched to provide a comprehensive literature search.

4.4.2.1 Electronic search strategy

Online database searches were conducted using Ovid Medline (1946 to January week 2, 2013), Embase (1980 to January week 2, 2013), PsychINFO (1967 to January week 2, 2013), Social Policy and Practice (1981 to January week 2, 2013), Cinahl Plus (1937 to January week 2, 2013), Allied and Complimentary Medicine (1985 to January week 2, 2013), The Social Sciences Citation Index (1970 to January week 2, 2013), and Scopus (1960 to January week 2, 2013).

Search strategies consisted of both Medical Subject Heading (MeSH) terms and keywords. The search strategy used for Medline is as follows: (the MeSH terms used are reported in italics), (exp *caregivers* OR caregiver* OR care giver* OR carer*) AND (*social support* OR *voluntary workers* OR *voluntary programs* OR *mentors* OR *telephone* OR *interne*t OR befriend* OR peer support* OR mentor* OR voluntary OR volunteer* OR social support* OR psychosocial intervention OR online OR internet OR telephone) AND (*depression* OR *anxiety* OR *mental health* OR *mental disorders* OR *social isolation* OR *social support* OR *self concept* OR *loneliness* OR *stress, psychological* OR *quality of life* OR depression OR anxiety OR mental health OR social isolation OR social support OR social inclusion OR social exclusion OR self worth OR selfworth OR self esteem OR selfesteem OR burden* OR hopeless* OR quality of life OR stress*) AND (*dementia* OR *dementia, vascular* OR

Alzheimer disease OR dement* OR Alzheimer* OR vascular dementia). The full example Medline strategy is available in Appendix 3.

4.4.2.2 *Searching of relevant systematic reviews*

From the electronic searching, relevant systematic review references were documented in order for the full texts to be sourced and their reference lists hand searched for further potentially relevant articles.

4.4.2.3 *Grey literature*

To find relevant studies unavailable in published journals, grey literature searches were performed. Six online websites and databases were searched using combinations of the following search terms: carer OR caregiver OR care giver AND befriending OR mentor OR peer support AND dementia OR Alzheimer's. The Alzheimer's Society website, the Mentoring and Befriending Foundation website, the Age UK website and the Joseph Rowntree Foundation website were searched, along with the grey literature databases Open Grey, UK Institutional Repository Search and Zetoc.

4.4.2.4 *Contact with professionals*

The primary authors of all included studies and other experts in the field identified through the literature searching were contacted. This was to find out if there were aware of unpublished articles they would be willing to provide for this review.

4.4.2.5 *Searching included studies*

The reference lists of all included studies were hand searched. All the full-text retrieved articles from electronic database searching were imported into the reference management software RefWorks. If the full-text was unavailable online, hard copies were sourced either from other academic institution libraries, contacting the authors or through an interlibrary loan service.

4.4.3 Quality assessment

Quality assessment of studies possible for inclusion in the review was undertaken using the QualSyst review tool (Kmet et al. 2004). This tool was chosen due to the ability to score a variety of different studies, the inclusion of a detailed scoring system and a manual for researchers to follow whilst scoring studies (Appendix 4). Quality scoring was conducted independently by two reviews (RS and NG), with disagreements being discussed and consensus achieved on the final quality scores.

Citing the lack of an empirically grounded quality assessment tool for use with a variety of study designs, Kmet et al. (2004) developed both a qualitative and quantitative scoring system (QualSyst) by drawing upon existing published tools. The QualSyst tool includes 14 questions for quantitative studies and 10 for qualitative studies and rates the answers to each question with a yes (2), partial (1) or no (0) outcome, with a maximum score of 28 for quantitative studies and 20 for qualitative studies. The quality score is reported as a percentage by dividing the score achieved by the maximum possible score. This quality assessment was then used to interrogate the studies based on their methodological quality. Studies were not excluded based on quality score.

4.4.4 Data extraction and management

Articles were grouped into qualitative, quantitative and mixed methods studies. Standardised data extraction forms were developed (Appendix 5). Data extraction for quantitative studies included author details, year of publication and publication type, participant demographics, sample size, intervention(s) investigated, outcomes measured, results of intervention impact (on both carers and volunteers) and key findings. Data extracted for qualitative and mixed methods studies included those for quantitative studies along with themes extracted from the results. To test whether the forms were adequate and no unnecessary information was being extracted, they were piloted at the beginning of the review process.

4.4.5 Data synthesis

There were insufficient data from quantitative studies for a meta-analysis to be performed. Information from both quantitative and qualitative studies was entered into a standardised table for comparison and identification of relevant results. The qualitative and quantitative data were then compared and contrasted in order to inform conclusions and directions for future research.

4.4.6 Changes after the completion of the protocol

A change from the protocol was the addition of a third data extraction form. In the protocol there were two, one for quantitative studies and one for qualitative studies. This third data extraction form is for the extraction of data from mixed methods studies. Under the heading 'Data extraction and management', it was suggested that two tables would be constructed, one for qualitative studies and one for quantitative studies. However, due to the small number of studies retrieved, it was decided to have one table combining all the extracted data.

4.5 Findings

The following section documents the results of the literature searches. In order for the review to be as transparent and complete as possible, the Preferred Reporting Outcomes for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher et al. 2009) was used as a guide. The PRISMA checklist is available in Appendix 6.

4.5.1 Results of literature search

4.5.1.1 Electronic searches

Eight electronic databases were searched using the search strategies previously described in section 4.4.2.1. A flow diagram detailing the search results is available in Figure 1. A search of Medline revealed 834 results, Embase 1005 results, PsychINFO 657 results, Social Policy and Practice 178 results, CINAHL plus 380 results, AMED 31 results, Social Sciences Citation Index 652 results, and Scopus 53 results In total, 3790 titles and abstracts were identified. After 1057 duplicates were removed, two researchers (RS and NG) independently examined the remaining 2733 results and compiled a list of references to be investigated further after examination of the titles and abstracts. This led to 80 full text articles being retrieved. After closer inspection, 65 studies were excluded and the remaining 15 were discussed between reviewers for potential inclusion. The references of the 76 retrieved but excluded articles are available in Appendix 7 with reasons for their exclusion. Four studies retrieved from the electronic searches were included in the final analysis (Charlesworth et al. 2008; Pillemer & Suitor, 2002; Sabir et al. 2003; Stewart et al. 2006). A breakdown of the included study characteristics, methodologies and results are available in Tables 4, 5 and 6. Reasons for article exclusion included interventions being professionally led, not befriending, mentoring, or peer support, and not being for carers of people with dementia.

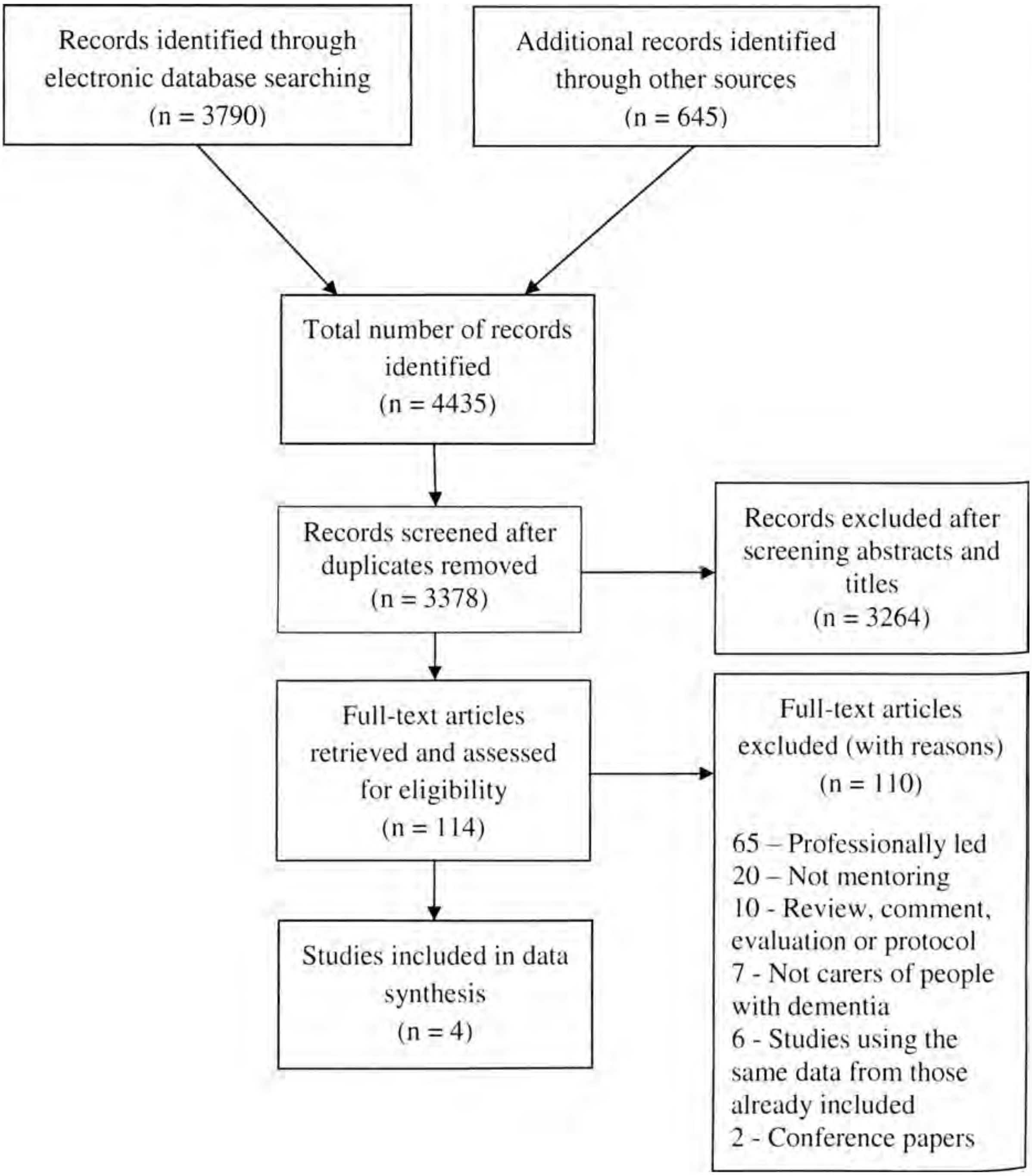


Figure 1. PRISMA flow diagram showing the process of including and excluding retrieved articles (Moher et al. 2009).

4.5.1.2 *Reference list searching retrieved reviews*

A number of relevant systematic reviews were identified from the electronic searches and 25 of these were retrieved, nine of which were repeats. As a result, 16 review reference lists were hand searched (the references of the reviews searched and the number of articles retrieved from each are available in Appendix 8). From this, 51 references were extracted and documented for further investigation. Upon closer inspection, it was found that 17 of the 51 articles were repeats from previous review reference lists, leaving a total of 34 articles. These 34 article references were checked against those found from the electronic searches, this resulted in a further 13 repeats being identified. The full texts of the remaining 21 articles were retrieved. After comparing the full text articles against the inclusion criteria, none were eligible to be included in this review and were subsequently excluded. The references of the excluded articles and reasons for their exclusion are available in Appendix 7.

4.5.1.3 *Grey literature searching*

In order to find articles not available through conventional electronic searching, grey literature searches were performed. Using the previously mentioned search strategy, a search of the Alzheimer's Society website revealed 101 results, the Mentoring and Befriending Foundation website no results, the Age UK website 179 results, the Joseph Rowntree Foundation website 260 results, Open Grey no results, the UK Institutional Repository Search 23 results and Zetoc nine results. This led to a total of 572 articles being identified. Of the 572 titles and abstracts reviewed, eight full text articles were sourced and checked for inclusion. Six were initially excluded from the review for not meeting the inclusion criteria, the final two studies were excluded after collaboration between the reviewers. The article references and reasons for their exclusion are available in Appendix 7.

4.5.1.4 *Contact with experts in the field of research*

Six authors were contacted to help identify additional material not identified in the literature searches. All of the first authors of the four included studies were contacted to ask if they were aware of any further studies which could be relevant to this review. One of the four authors responded, but no further studies were identified for possible inclusion. A further two authors identified as experts in the field of carer research from the initial literature searching were contacted but neither responded.

4.5.1.5 Reference list searching of included studies

From the reference lists of the four included studies (Charlesworth et al. 2008; Pillemer & Suitor, 2002; Sabir et al. 2003; Stewart et al. 2006) a further 22 references were identified as requiring further investigation. Of these, 16 were repeats from either the earlier electronic searches or reference searching of relevant reviews. Full text article of the remaining six were retrieved and examined for possible inclusion. Three of the articles were retrieved from Charlesworth et al. (2008) and three from Pillemer & Suitor. (2002). All six failed to meet the inclusion criteria.

4.5.2 Included studies

In total, 17 studies were discussed between reviewers (RS and NG) and four studies were included in the final data synthesis. All four came from the initial electronic database searching. The references and reasons for exclusion of the 110 full text articles retrieved from the literature searching and then excluded based on the inclusion criteria, are available in Appendix 7.

For ease of reporting, the volunteer mentoring services will be broken down by type into peer support and befriending.

4.5.2.1 Characteristics of included studies

All four studies originated from either North America (3) or the UK (1). Two of the articles originated from the USA (Pillemer & Suitor, 2002; Sabir et al. 2003), one from Canada (Stewart et al. 2006). The other was from the UK (Charlesworth et al. 2008). Two studies were randomised controlled trials (Charlesworth et al. 2008, Pillemer & Suitor, 2002), one study was observational (Sabir et al. 2003) and the fourth was qualitative in design (Stewart et al. 2006). The quantitative studies had a combined sample of 284 participants in the intervention groups and 181 controls (Charlesworth et al. 2008, Pillemer & Suitor, 2002; Sabir et al. 2003). The qualitative study consisted of 66 participants, 47 of which were carers of people with dementia (Stewart et al. 2006). Overall, participants had an average age of 62 years across all four studies but the average ages of the participants for the peer support services ranged from 58 years to 62 years. For the befriending service the average age of participants was 68 years. Female participants outnumbered male participants. This ranged from 36% males and 64% females for Charlesworth et al. (2008) and 25% males and 75% females for Sabir et al. (2003). Ethnicity of participants was only reported in one study (Charlesworth et al. 2008), which included 99% White participants overall (98% in the control group and 100% in the intervention group). All but one study (Stewart et al. 2006) focused on carers of people with dementia exclusively. Stewart et al. (2006) also included carers of stroke survivors. This study was included in this review as the majority (60%) of participants were carers of people with dementia. Full details of characteristics of the included studies are available in Table 4.

A variety of different outcomes were measured across the four studies. Two focused on mental health outcomes for carers (Charlesworth et al. 2008; Pillemer & Suitor, 2002), one looked at carer and volunteer mentor similarity and continuation of visits (Sabir et al. 2003), and the final study investigated the types of support offered by peer volunteers and carer satisfaction with the service (Stewart et al. 2006). Of the four included studies, two focused on face-to-face peer support (Pillemer & Suitor, 2002; Sabir et al. 2003), one on telephone peer support (Stewart et al. 2006) and one on face-to-face befriending (Charlesworth et al. 2008).

The studies varied on the detail provided of their inclusion criteria. In several, the inclusion criteria were that the participants had to be the primary carer of a person with dementia (Pillemer & Suitor, 2002; Sabir et al. 2003, Stewart et al. 2006). Charlesworth et al. (2008) went further and stipulated that carers had to be: aged 18 years or older, caring for a person with dementia and spending at least 20 hours a week on care related tasks. Another main difference in the inclusion criteria was that Stewart et al. (2006) included carers who were not cohabiting with the person they were caring for. No studies were found which investigated mentoring for carers of people with dementia. Full details of the methodology of included studies are available in Table 5.

4.5.2.2 *Methodological quality of included studies*

The result and overall quality scores of included studies are documented in Table 6. A full breakdown of the quality scores for quantitative studies is available in Table 7 and the qualitative study in Table 8. The average quality score across all four studies was 75%. One received a score of 100% (Charlesworth et al. 2008), with the others receiving 71% (Pillemer

& Suitor, 2002) and 65% (Sabir et al. 2003; Stewart et al. 2006). Taken separately, the quantitative studies were of higher quality than the qualitative study, averaging a score of 79% compared to 65%. The main issues with the quantitative studies tended to be a lack of estimates of variance (Pillemer & Suitor, 2002; Sabir et al. 2003), and whether or not blinding of investigators was conducted (Pillemer & Suitor, 2003). The main issues with Stewart et al. (2006) were that no verification procedures were reported, and there was no account of reflexivity of sources of investigator influence on the results obtained. Three of the four studies documented attrition (Charlesworth et al. 2008; Pillemer & Suitor, 2002, Stewart et al. 2006), but only Charlesworth et al. (2008) and Stewart et al. (2006) documented reasons for participant withdrawal. Attrition ranged from between 19% in the Charlesworth et al. (2008) study, 22% for Pillemer and Suitor (2002) and 30% for Stewart et al. (2006). Without knowing levels of attrition from the Sabir et al. (2003) study, it is not known if participant withdrawals were excluded from the analysis which therefore increases the chances of bias.

4.5.2.3 Peer support

Two studies investigate face-to-face peer support for carers of people with dementia (Pillemer & Suitor, 2002; Sabir et al. 2003) and one telephone peer support (Stewart et al. 2006). Although both face-to-face peer support studies looked at different outcomes, neither found a statistically significant effect on the outcomes measured. Pillemer & Suitor (2002) found no positive effects for either depression or self-esteem for carers, although it was reported in secondary analysis that peer support had a modest buffering effect on disruptive behaviours and depressive symptoms for carers experiencing the most stressful situations. This intervention study took place over eight weeks with the intervention taking place once a week and lasting from between one and two hours a time. Qualitative data highlighted that carers found that experiential similarity was one of the most positive features of the project. Disruptive behaviours and methods of dealing with them was a common theme discussed between carers and volunteers. Carers reported a high level of satisfaction with the peer support service and the volunteers reported that they found it an enjoyable experience on 95% of occasions. The authors concluded that peer support for carers of people with dementia is not an effective intervention when offered as a standalone intervention, despite the positive qualitative findings.

Sabir et al. (2003) investigated carer and peer supporter similarity on a range of dimensions, but reported no significant differences in the outcomes measured (number of visits, continuation of visits post intervention and quality of match). This study lasted for eight weeks with the intervention taking place once per week for between one and two hours per time. The carers' and peer supporters' relationships were investigated for similarity on structural similarity (marital status, employment, age and education), appraisal similarity (satisfaction with caregiving, satisfaction with day-to-day support, stress of caregiving, positive aspects of caring, satisfaction with emotional support, feeling of neglect by family and friends), psychological similarity (self-esteem and depression) and experiential similarity. Contrary to expectations, carer and peer supporter pairs completed more visits when dissimilar on feelings of neglect, depression and current caregiving. There was also a trend for pairs to continue meeting after the project ended when they differed on perceived positive aspects of caregiving. Finally, it was judged the pairs were positive matches more often when they differed in the emotional stress of caring. It was concluded that extensive matching was not essential for a successful peer support intervention for carers of people with Alzheimer's disease; only the shared experience of being carer was likely to enhance the relationships.

The qualitative study (Stewart et al. 2006) investigated telephone peer support. This intervention lasted 20 weeks, with the intervention lasting from between 15 minutes to more than one hour, once per week. Content analysis was performed on the data. The results showed increased satisfaction with support, coping skills, caring competence and confidence, and decreased carer burden and loneliness. In particular, half of carers described feelings of increased confidence and competence due to the support from peer supporters. Carers also reported receiving significant emotional support from the telephone peer supporters, which was seen as vital as carers reported losing support from family and friends following diagnosis of the person they were caring for. Other reported impacts of the interventions were a decrease on reliance of other forms of social support, enhanced coping ability (more than half of carers reported this), reduced feelings of loneliness (37% of carers reported this), a reduction in feelings of burden due to the information obtained from peer supporters (reported by 16% of carers) and finally there was 90% satisfaction with the service. It was noted that the intervention did not have an impact on carers' use of health related services, however 14% of carers reported accessing services they did not previously know about due to the information provided by peer supporters. It was reported that most of the positive impact came from the peer supporter's experiential knowledge of the carers' situation, and that experiential similarity is highly important. It was concluded that telephone peer support for carers has a positive impact on caring ability, provides an accessible, cost-effective and efficient means of communication with current carers.

4.5.2.4 Befriending

One study investigated face-to-face befriending for carers of people with dementia (Charlesworth et al. 2008). The intervention duration was 104 weeks with carers being offered access to a befriending facilitator, but only around half the carers took up the service. For those carers who took part in befriending, the intervention took place once a week and lasted approximately one hour per visit for six months or more. The results showed no statistically significant benefits of the intervention over the control group for either psychological well-being or cost-effectiveness. No improvement was found for carers in the intention to treat population, as measured by the Hospital Anxiety and Depression Scale (HADS), ($p = 0.71$). However, carers receiving the befriending intervention for at least six months reported a significant improvement in depression scores at 15 months follow up ($p = 0.04$). Across the secondary outcomes measures, there were no statistically significant positive effects for the intervention over the control group. Finally, there was no statistically significant evidence for the cost-effectiveness for befriending. The intervention costs was £106,000 per quality-adjusted life-year (QUALY) gained, as opposed to the typical cost of £20,000-£30,000 per QUALY gained.

The authors suggested that if uptake of the befriending service could be improved, positive outcomes were more likely to be found in the intention to treat population, although due to the low uptake it could be that carers do not necessarily want befriending services. It was concluded that access to a befriender facilitator for carers of people with dementia was not an effective intervention. Whilst it was suggested that future research into befriender facilitators was not necessary due to the negative findings, research should focus on befriending for carers of people with dementia who receive the service for six months or more because of the trend towards a significant reduction in depression scores.

Table 4. Characteristics of included studies

Authors (year published)	*Aims/ hypotheses*	*Study location*	*Sample size*	*No. of participants*	*No. of controls*	*Mean age of carers in years (standard deviation)*	*Mean age of volunteers in years (standard deviation)*	*Gender ratio of participants (M:F %)*	*Participant ethnicity recorded?*
Charlesworth et al. (2008)	Whether having access to a befriender facilitator is effective when compared with usual care.	UK	236	116	120	68 (11.4)	NR	36-64%	Yes. 99% of participants were recorded as White.
Pillemer & Suitor (2002)	To test if adding peer support to carers' social network produces positive outcomes.	USA	147 -115 completed.	54	61	58 (NR)	NR	29%-71%	No
Sabir et al. (2003)	To identify the predictors of successful carer and peer relationships.	USA	114 (57 matched carer and peer supporter pairs).	114	NR	62 (NR)	62 (NR)	25%-75%	No
Stewart et al. (2006)	Understanding the impact of telephone peer support for carers.	Canada	66 (47 were carers of people with dementia).	66	N/A	60 (13.88)	64 (7.46)	34%-66%	No

NR = not reported

Table 5. Methods of included studies

Authors (year published)	Interventions investigated (face-to-face unless otherwise stated)	Participants recruited from?	Study design	Study period (weeks)	Length of intervention (hours)	Inclusion criteria	Exclusion criteria	Outcomes measured (data collection methods and scale(s) used)
Charlesworth et al. (2008)	Befriending	Norfolk and Suffolk through mail outs from GP surgeries, leaflets sent to various organisations, press articles and presentations.	Randomised controlled trial with an economic evaluation.	104	1	Family carers aged 18 or older, caring for a person with dementia. At least 20 hours a week spent on care related tasks.	Carers with cognitive impairment or terminal illness. Carers of people in permanent residential accommodation.	Anxiety and depression (HADS), Loneliness (two item measure), Positive and negative affectivity (PANAS) Burden (CADI), Relationship quality (MCBS), Coping (COPE), Social support (PANT), Life events (LTE), Health related quality of life (EQ5-D), Resource use (semi-structured interviews), Support from family and friends (participant interviews).
Pillemer & Suitor (2002)	Peer support	State University of New York Health Science	Mixed methods. Randomised controlled trial with a	8	1-2	Person being cared for had to have a diagnosis	PWD could not reside in a nursing home at the pre-intervention	Depression (CES-D) Self-esteem (RSES) Satisfaction with the service (participant interviews).

		Centre.	*qualitative aspect.*			*of AD.*	*interview stage.*	
Sabir et al. (2003)	*Peer support*	*State* University of New York Health Science Centre.	Observation study.	8	1-2	Person being cared for had to have a diagnosis of AD.	Person being cared for could not reside in a nursing home at the pre-intervention interview stage.	Number of volunteer visits, continuation of visits post-intervention and quality of the carer/peer supporter match.
Stewart et al. (2006)	Telephone peer support	Contact with relevant agencies, posters, presentations to groups, newspaper advertisements and mail-outs to relevant organisations and services.	Qualitative.	20	15 minutes to over an hour.	Carers of a person with dementia or person diagnosed with stroke.	People being cared for who were under the age of 50.	Types of support provided by peer supporters, support processes, perceived intervention impacts and satisfaction with the intervention.

AD = Alzheimer's Disease, HADS = Hospital and Anxiety Depression Scale, PANAS = Positive and Negative Affect Schedule, CADI = Carers Assessment of Difficulties Index, GP = General Practitioner, MCBS = Mutual Communal Behaviours Scale, COPE = Coping Orientation for Problem Experience, PANT = Practitioner Assessment of Network Type, LTE = List of Threatening Experiences, CES-D = the Centre for Epidemiological Studies Depression Scale, RSES = Rosenberg Self-Esteem Scale, EQ5-D = EuroQol 5 Dimensions, PWD = person with dementia.

Table 6. Results of included studies

Authors (year published)	Results of intervention(s) on carers	Results of intervention(s) on volunteers	Themes extracted (for qualitative or mixed methods studies)	Measure used to rate participant withdrawals	Number of participants who withdrew (n-%)	Authors' conclusions	Quality score (%)
Charlesworth, et al. (2008)	No statistically significant effect across the outcomes measured.	NR	N/A	Reasons for participant withdrawal included the death of the carer and carer ill health.	46 (19%)	Befriending for carers of people with dementia is not an effective intervention.	100
Pillemer & Suitor (2002)	No positive effects were found for either depression or self-esteem.	NR	Experiential similarity. Sharing experiences with someone who has been through something similar was seen as highly important to carers.	NR	32 (22%)	Peer support for carers of people with dementia is not an effective intervention.	71
Sabir et al. (2003)	No significance was found between carer/peer	NR	N/A	NR	NR	Extensive matching criteria is not essential for a successful peer	65

	supporter similarity and number of visits made.					support intervention for carers of people with AD.	
Stewart et al. (2006)	There was an increase in satisfaction with support, coping skills, care giving competence and confidence, and decreased caregiver burden and loneliness.	NR	Carers knowing that they are not alone. Also someone is there who understands what they are going through, so experiential similarity is seen as important.	Participant withdrawal documented with reasons. They included the ill health of the person cared for and carer constraints.	20 (30%)	Use of telephone peer support provides an accessible, cost-effective and efficient means of communication to carers.	65

NR = not reported

Table 7. Details of quality scoring for the included quantitative studies (Kmet et al. 2004)

Scoring criteria	Charlesworth et al. (2008)	Pillemer & Suitor (2002)	Sabir et al. (2003)
Question/objective sufficiently described?	2	2	2
Study design evident and appropriate?	2	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	0
If interventional and random allocation was possible, was it described?	2	1	N/A
If interventional and blinding of investigators was possible, was it reported?	2	0	N/A
If interventional and blinding of subjects was possible, was it reported?	N/A	0	N/A
Outcome and (if applicable) exposure measure(s) well-defined and robust for measurement/misclassification bias? Means of assessment reported?	2	2	2
Sample size appropriate?	2	1	1
Analytic methods	2	2	1

described/justified and appropriate?			
Some estimate of variance is reported for the main results?	2	0	0
Controlled for confounding?	2	2	N/A
Results reported in sufficient detail?	2	2	1
Conclusions supported by the results?	2	2	2
Total score/possible maximum score	**26/26**	**20/28**	**13/20**

Table 8. Details of quality scoring for the included qualitative study (Kmet et al. 2004)

Scoring criteria	Stewart et al. (2006)
Question/objective sufficiently described?	2
Study design evident and appropriate?	1
Context for the study clear?	2
Connection to a theoretical framework/wider body of knowledge?	2
Sampling strategy described, relevant and justified?	1
Data collection methods clearly described and systematic?	1
Data analysis clearly described and systematic?	2
Use of verification procedure(s) to establish credibility?	0
Conclusions supported by the results?	2
Reflexivity accounted for?	0
Total score/possible maximum score	**13/20**

4.6 Discussion

This review highlighted both the paucity of studies and the inconsistent findings in the available literature for the effectiveness of volunteer mentoring services for carers of people with dementia. This is a concern as it is likely these services will increase in number (DoH, 2009). It also highlighted the differences in qualitative and quantitative findings. Although the quantitative results largely showed no impact of volunteer mentoring, qualitative findings suggested carers value both the support the services offer and the experiential similarity of the volunteers. Overall, the findings of this review are in line with previous research, which reports a lack of demonstrated efficacy for interventions for carers of people with dementia (Arksey, 2003; Mead et al. 2010). However, the results suggesting the importance of experiential similarity have also been reported elsewhere (Pillemer & Suitor, 1996; Pillemer & Suitor, 2002; Suitor et al. 1995) making this an important area for further exploration.

4.6.1 Differences in how the services operate

There were similarities between befriending (Charlesworth et al. 2008) and peer support (Pillemer & Suitor, 2002; Sabir et al. 2003; Stewart et al. 2006) in terms of how they operate. Typically, the interventions lasted one hour at a time and took place once a week. However, overall there was more flexibility reported for the telephone peer support intervention (Stewart et al. 2006) which could last from between 15 minutes to two hours. The most notable difference between the services was that peer support requires volunteers to have prior caring experience, whereas befriending did not. However, as few studies were identified, caution is needed when comparing these types of volunteer mentoring services.

4.6.2 Impact on carers and volunteers

The studies investigated numerous outcomes including depression, anxiety, perceived social support, self-esteem, number of volunteer visits, and satisfaction. Quantitative interventions of befriending and peer support were shown to be ineffective at reducing mental health issues and loneliness in carers (Charlesworth et al. 2008; Pillemer & Suitor, 2002). However, the qualitative study (Stewart et al. 2006) reported that carers described reduced burden and loneliness, both of which have been correlated with levels of stress and mental health issues (Beeson, 2003; Leggett et al. 2011). Further research could help clarify the reasons for this finding. It is possible that the study by Stewart et al. (2006) which focused on telephone peer support, offered a more flexible and effective means of communication and support with carers, leading to better outcomes. However, the differences in research design could explain the differing findings, as research has shown participants report more positively or negatively depending on how the data are collected (Greenwood et al. 1999). The small but significant difference shown in depression scores at 15 months for carers who received befriending for at least six months (Charlesworth et al. 2008) could indicate that the benefits of befriending might not be immediate, and therefore more longitudinal studies are needed. Also, it is possible that the use of validated outcome scales (Charlesworth et al. 2008; Pillemer & Suitor, 2002) may not be focusing on the aspects of volunteer mentoring which are most important to carers. This could, in part, explain the differences found between the quantitative and the qualitative investigations. Although there have been a number of benefits attributed to volunteering (Piliavin & Siegl, 2007), none of the studies included here investigated the impact of volunteering on befrienders, mentors, or peer supporters, making it an important area for future exploratory investigations.

4.6.3 Developing successful carer and volunteer mentor relationships

The development of successful volunteer mentoring relationships was thought to be associated with the experiential similarity of volunteer mentors. The importance of this was reported by three of the included studies (Pillemer & Suitor, 2002; Sabir et al. 2003; Stewart et al. 2006). In particular, Sabir et al. (2003) reported that it was not essential to undertake extensive matching prior to pairing carers and volunteer mentors, but it was important that volunteer mentors had previous experience of caring. In fact, it was shown that dissimilar pairs had more contact than pairs matched across a wide range of demographics. In this review, the finding of the importance of experiential similarity is consistent with the findings from previous research (Pillemer & Suitor, 1996; Suitor et al. 1995) and highlights that extensive matching criteria are unnecessary. However, more research is needed to explore what it is about experiential similarity that makes it important in volunteer mentoring relationships.

4.6.4 Quantitative versus qualitative findings

This systematic review not only demonstrated the lack of research on the use of volunteer mentoring services for carers of people with dementia, it has also highlighted inconsistencies in the literature among qualitative and quantitative findings. Whilst the quantitative results showed largely negative results, qualitative findings showed that carers value the support the services offer. There could be a number of reasons for these differences but understanding this is difficult because few, rather diverse studies were included. Possibly, differences in article inclusion criteria could have had an impact. For example, it could be that the qualitative study (Stewart et al. 2006) reported positive findings because some of the carers were not living with the person with dementia. Subsequently their stress levels and perceived burden were potentially already lower to begin with. Secondly, it could indicate that mentoring services take a longer period of time to have an effect. Although findings from Charlesworth et al. (2008) showed no improvements in carer depression when offered access to a befriender facilitator, a significant improvement in depression scores for those carers who used a befriending service for at least six months was reported. This could also possibly explain the lack of significant findings found by Pillemer and Suitor (2002), as the peer support intervention in this study lasted eight weeks.

Whilst there were conflicting findings between the qualitative and quantitative studies, there was also disparities within one study. Pillemer and Suitor (2002) reported that peer support was not an effective intervention in terms of the quantitative findings but when participants were asked about the service and the benefits it offers them, the limited amount of included qualitative data showed that carers found an opportunity to discuss difficult topics, such as disruptive behaviours and how best to deal with them very useful. This again could suggest that the length of time carers engage with volunteer mentoring could be a factor, as it could take time for the carer to build up trust with the volunteer and start to share the difficulties they are experiencing. This was reported by the peer supporters having had experience of the situations themselves and being able to pass on their knowledge.

4.6.5 Limitations of included studies and their possible impact on findings

There were a number of limitations of the included studies. Firstly, the levels of participant withdrawal from both the research and interventions is of concern. Stewart et al. (2006) reported 30% of the participants withdrew from the study over the course of the of the 20 week intervention period, which was considerably more than the 19% reported by Charlesworth et al. (2008) and 22% by Pillemer and Suitor (2002). The two studies which did report reasons for participant withdrawal highlighted the ill health of the carers as an overriding factor. The high level of withdrawal from the Stewart et al. (2006) study is an important factor that needs to be taken into consideration when examining the results. Attrition bias could have led to only the healthiest and carers who were already coping well completing the study, suggesting that those who did not find the peer support useful may have dropped out early. Also, although the authors noted that those who withdrew did not give dissatisfaction with the peer support as a reason, it may be that carers felt ill health may be a more acceptable answer to give for leaving the intervention. Overall, this limitation could partially explain the positive results found for the peer support service, with further investigation needed to identify if these findings can be replicated.

Charlesworth et al. (2008) reported low uptake of befriending by carers, despite having access to a befriender facilitator. This limits the generalisability of the results. Those who did take part for six months or more provided weak evidence for its benefit on improving depression scores compared to the control group. The low number of carers who continued with befriending for six months or more is unfortunate, as a higher number may have produced stronger evidence for its impact in reducing depression in this population and limits the conclusions that can be drawn. However, this low uptake could be a reflection of the general reluctance carers often have in accepting formal support (Brodaty et al. 2005; McCabe et al. 1995).

4.6.6 Strengths and limitations of the review

The main strength of this review is the large amount of literature that was examined across a number of different sources, the inclusive nature of the research design and its specific focus. Previous reviews have looked more generally on the impact of support services for carers of people with dementia (Etters et al. 2008; Mead et al. 2010). However, a main limitation of this review is the dearth of published and unpublished research, which resulted in only four studies being included. This highlights a lack of research in this field and influences the power of the conclusions that can be drawn from the results. A second limitation is that only articles published in English were included, which could have led to potentially important studies being missed.

4.6.7 Future directions

Given the lack of clarity in terms of differences and similarities between the various types of volunteer mentoring services, further research is required and this is explored in Chapter Five. This is potentially an important area of future research to help improve understanding of the models of volunteer mentoring which work best, possibly leading to more effective services being offered. This could include comparisons of volunteer mentoring with similar interventions that are professionally led. No studies investigated the impact of volunteering on the volunteer mentors. Given the evidence that there could be a positive impact on volunteers' well-being, (Musick & Wilson, 2003; Piliavin & Siegl, 2007) future research is needed to identify the impact, if any, on volunteers providing volunteer mentoring.

The English government's policy surrounding carers of people with dementia and volunteers is clear (DoH, 2009); more volunteer mentoring services are needed to help support carers in the community. However, the little research which exists does not overwhelmingly support this assumption.

4.6.8 Relation of the review findings to the thesis theoretical perspectives

The findings of this review have connections to the theoretical frameworks documented in Chapter Two. The importance of experiential similarity over structural similarity (matching demographic characteristics) fits with conclusion drawn by Suitor et al. (1995) concerning which aspect of homophily is most important in the successful development of empathic relationships. However, due to the lack of studies found by this review, an exploration of how the services are operating and if they have criteria whereby matching is based on structural, experiential similarity or both were warranted. This is expected to help improve understanding of how these services are operating in practice and if any theoretical perspective underlies the intervention and is applied when matching carers and volunteers. Since no studies looking at the impact of volunteer mentoring on volunteers were found, it is not possible to relate the findings from previous studies regarding the importance of reciprocity (in particular SET) to the finding presented here. However, it does highlight the need for further research in understanding the processes involved in volunteer mentoring and the potential impact on volunteers.

4.6.9 Published studies since the completion of this review

Since this systematic review was completed in January 2013, there have been two articles published which may have had an impact on the conclusions drawn and the direction of future research relating to this PhD. For example, Greenwood et al. (2013) investigated the impact and experiences of peer support on carers of people with dementia and volunteers. This study would have fitted the inclusion criteria (as documented in section 4.3.1). A further study by Greenwood and Habibi (2014) investigated the impact of mentoring on carers, however the authors did not distinguish between carers of people with dementia and other carers and therefore did not fit the criteria here. Additionally, the impact of peer support on volunteers has since been explored by Brooks et al. (2014) who highlighted the overall positive effect on former carers, including emotional gains, a greater sense of connection with others and widening of their social networks. However, these authors and Greenwood et al. (2013) also highlighted that peer support could be stressful for former carers due to the negative emotions evoked from memories of prior caring. These additional studies will be discussed in relation to the research findings presented in Chapter Eight.

4.7 Conclusions

There was very little quantitative evidence that volunteer mentoring services are effective at improving outcomes, such as carers' mental health, social isolation or quality of life. However, qualitative evidence suggests that carers value the services and the opportunity to talk about the difficulties they were experiencing. The importance of experiential similarity in volunteer mentoring relationships was one of the most significant aspects highlighted by this review. No included studies found investigated the impact on volunteers which is perhaps surprising. Future research is needed to understand the inconsistencies between the quantitative and qualitative findings and explore the experiences of the volunteers. On completion of the review, in order to understand how volunteer mentoring services were operating in England, a survey of services managers and volunteer coordinators was conducted (Chapter Five).The findings from both the systematic review and survey of services contributed to the development of the research questions for Phase Two of this research.

5 Chapter Five: Survey of volunteer mentoring services

5.1 Introduction

The systematic review (Chapter Four) showed differing evidence for the effective use of volunteer mentoring for carers of people with dementia. This is despite previous research reporting it as having a positive impact in other populations (Cattan et al. 2005; Dean & Goodlad, 1998; Dennis et al. 2009; Greenwood & Habibi, 2013; Mead et al. 2010; Veith et al. 2006). In order to clarify what is actually happening currently, it was decided to undertake a survey to interview service managers and volunteer coordinators to help better understand the services' aims and what was considered important for developing supportive volunteer mentoring relationships. The findings from this survey coupled with those from the systematic review (Chapter Four) helped guide the research questions for Phase Two. In keeping with the pragmatic approach of the thesis, the survey included questions which required either yes or no responses, or questions which required the participant to explore their perceptions and experiences of managing a volunteer mentoring service. The publication resulting from this chapter (Smith & Greenwood, 2014b) is available in Appendix 9.

First, the survey aims and research questions are documented. This is followed by a description of the methods, which explain the data collection process and the rationale for using content analysis. Next, the findings of the survey are explored, reporting where services are similar or different, and the findings relating particularly to carers and volunteers. Finally, the findings are discussed in relation to those reported in the systematic review (Chapter Four), how they fit with background research (Chapter Two) and UK government policy (Chapter Three). Finally, the survey limitations and future directions are discussed.

This survey explored the first research question of the thesis documented in section 1.2:

1. What is the range of volunteering mentoring services in England offered to carers of people with dementia?

5.2 Aims

The primary aim of the survey was to understand the similarities and differences between the various types of volunteer mentoring services in England. For example, the manner in which they operate and what outcomes were intended for carers and volunteers. It also aimed to investigate how volunteers were recruited and any issues there were in retaining them. In order to gain understanding of the range of volunteer mentoring services available, the survey also included services which offered a variety of support models, including face-to-face and telephone support.

5.2.1 Research questions:

1. What are the similarities and differences between the services?
2. What are the range outcomes for carers and volunteers the services aim to achieve?
3. What roles do experiential similarity and matching have in the development of volunteer mentoring relationships?

5.3 Methods

5.3.1 Study design

The design was a survey method (Groves et al. 2009) by researcher telephone interview using a questionnaire designed specifically for the study. The protocol and ethics approval for this survey are available in Appendix 10.

5.3.1.1 Service inclusion and exclusion criteria:

Inclusion criteria:

- The services offered a befriending, mentoring or peer support service for carers, including carers of people with dementia.
- The services offered either face-to-face, telephone support or a combination of both
- Volunteers delivered the intervention.
- The services addressed the needs of carers.

Exclusion criteria:

- Inability to identify if carers of people with dementia were accessing the service.
- If paid employees were delivering the intervention.
- If carers were paying for the service.
- If the service had stopped operating more than six months prior to the start of data collection.

5.3.1.2 Service identification

The services to be approached were initially identified by internet searching, with the aim of asking contacted services if they knew of others and building a list of contactable services (snowballing). The 'snowballing' approach had limited success with only one befriending service being identified in this way. The majority of services were identified through internet searching using combinations of the search terms 'befriending', 'peer support', 'peer mentoring'. 'mentoring', 'carer', 'dementia' and 'Alzheimer's'.

5.3.1.3 Data collection tool

The questionnaire contained a mixture of closed and open ended questions. For example, it sought to identify details such as the numbers of volunteers and carers enrolled in the service. The questionnaire consisted of 25 questions and was split into three sections: general questions about the service (for example, its aims and length of time operating), questions about the volunteers (for example, number of volunteers, training and supervision) and questions about the carers (for example, number of carers accessing the service and how they are recruited). Specific questions were asked about matching criteria and volunteers' experiential similarity in an attempt to expand on the findings from the systematic review (Chapter Four). The questionnaire took approximately 20 minutes to complete over the telephone. Participants were informed beforehand that it could take up to 30 minutes to complete the questionnaire. Copies of the questionnaire (Appendix 11) were also sent by email (which was the preferred method of participants for questionnaire completion). It is not known how long it took to complete in this way

5.3.1.4 Piloting the questionnaire

The questionnaire was piloted on two co-researchers and also two managers or volunteer coordinators from relevant organisations to highlight any potential problems with specific questions in terms of being clearly understood. This led to a number of changes being made to the questionnaire from the original version, including a reduction in the number of questions, removing questions which appeared to be repeating those previously asked and the addition of follow up questions to illicit a more in-depth response. It also identified the questions being used were appropriate for managers or volunteer coordinators and would receive the most comprehensive responses. There was the opportunity for participants taking part in piloting to highlight any questions they thought should be asked which were missing from the questionnaire, however no further questions were added. The questionnaire was piloted in August 2012 and data were collected between September 2012 and January 2013.

5.3.1.5 Sample

This survey initially set out to recruit a purposeful sample of five services from each type of volunteer mentoring project (befriending, mentoring and peer support). Fifteen were contacted at first either by email or by post and followed up with a telephone call. For every manager which declined, another was contacted until fifteen confirmed their participation. In total, thirty three services were contacted across England. From the fifteen managers who confirmed they wished to take part, six returned the questionnaires within two weeks. A follow up telephone call or email was made to the remaining nine managers. This resulted in a further three questionnaires being returned before the cut-off time, which was set at four weeks after initial agreement to participate. This cut-off time for the return of questionnaires was important to allow the data analysis to be completed and the progression onto developing the research questions of the thesis. As a result, nine completed questionnaires were analysed.

5.3.2 Study procedure

Once a service was identified, an information letter (Appendix 12) was sent out to the manager or volunteer coordinator. This introduced the survey, what their participation involved and also that the letter would be followed up with a telephone call approximately one to two weeks later. After two weeks had passed, services were telephoned and an attempt was made to speak to the person the letter was addressed to. The potential participant was then asked if they had received the letter and if they would like to participate in the survey, and if so when would be a convenient time for the interview to take place. If they had not read the letter, an explanation of its contents and the purpose of the survey were provided. If the potential participant declined to take part, they were thanked for their time and the call was ended. All participants were informed their responses would be confidential and that interviews would be anonymised and identified by code only.

The majority of telephone calls were expected take place between 9am and 5pm Monday to Friday, although if a service manager or volunteer coordinator preferred to complete the interview outside of these times exceptions were made. The telephone interviews were recorded with a digital recorder and this was explained to participants before the interview began. If the participant declined to the interview being recorded, their answers were recorded manually. Before moving on to the next question, care was taken to ensure all information from the response was documented. For those managers who were unable to be interviewed by telephone or preferred a different method of completing the questionnaire, they were offered it by email or post (with a stamped addressed envelope provided). Participants were asked to try and return the questionnaire within two weeks. The information returned in this format was treated in the same confidential manner as that from telephone interviewing. All data were anonymized and stored securely on a password protected University computer.

5.3.3 Non-response

All telephone calls made were documented. This included phone calls which were unanswered or participants refused and the services which did not meet the inclusion criteria described above. Several attempts to contact the service managers or volunteer coordinators were made before it was recorded as a non-response. If it was found that a service had stopped operating, a question was asked (if someone was contactable from the parent organisation) regarding the reasons for the closure of the service.

5.3.4 Data analysis

Data from the face-to-face and telephone volunteer mentoring services were grouped together and categorised by volunteer mentoring type. Quantitative data, such as the number of volunteers and carers was recorded in Excel. Qualitative data were inputted into a Word table for later analysis. Data were content analysed (Krippendorff, 1989) using qualitative data analysis software Atlas.ti version 6.0 (Murh, 2008). Content analysis was chosen as the responses to the questionnaire were expected to be brief (due to the majority of participants completing them over email) and contain data which would be best analysed through frequency counting. Themes developed from the content analysis were reviewed by two researchers (RS and NG).

Descriptive statistics (e.g., number of volunteers and carers per service) were entered into a table for ease of reporting. Quantitative content analysis involved the counting of frequencies of content in the responses of the managers and volunteer coordinators. Studies using quantitative content analysis have been described as:

> "*Typically, a study using a summative approach to qualitative content analysis starts with identifying and quantifying certain words or content in text with the purpose of understanding the contextual use of the words or content*" (Hsieh & Shannon, 2005, p. 1283).

Data were input into an Atlas.ti database and coded in order to produce frequency counts of responses to the specific questions on the survey questionnaire. Content analysis is often used in this way, as described by Franzosi (2008, p. xxi):

"*...quantitative content analysis...consists of tabulating the occurrences of content units*"

5.3.5 Ethics approval

Ethical approval was sought from the Kingston University Faculty Research Ethics Committee (FREC) on 14/05/2012 and granted on 26/06/2012. Ethical considerations were documented using the Economic and Social Research Council Framework for Research Ethics (ESRC, 2010) as a framework. A copy of the ethics application form is available in Appendix 10.

5.3.5.1 Ethical conduct

All service managers and volunteer coordinators who agreed to take part in the survey were informed before participation that their answers were confidential. Only the names of contacted organisations were documented to make sure none were called twice, these were then destroyed securely upon completion of data collection. They were also informed that only the type of service operating (befriending, mentoring or peer support) and general location (for example, London or South East England) would be documented and used in the thesis and any future publications.

Informed consent for this survey was obtained verbally prior to starting data collection. Service managers and volunteer coordinators were fully informed of the purpose of the research with an information letter sent beforehand. This was then repeated verbally during the initial telephone call informing them of what the interview consisted of in terms of the estimated length of time it may take and number of questions to be asked. The participants were informed prior to starting the interview that they could withdraw at any time or only answer selected questions without giving a reason and the information they have provided would be destroyed if they wished.

All participants indicated they would like to receive a summary of the findings. This is available in Appendix 13.

5.4 Results

5.4.1 Participating service details

Of the nine service managers and volunteer coordinators that participated in the survey six were befriending services, two were peer support and one mentoring. Of these, five offered face-to-face support, three telephone support and one offered a mixture of both depending on carers' needs (Table 9). Carers of people with dementia were accessing the services at the time of data collection.

Table 9. Volunteer mentoring type and method of service delivery

		Number
Service types		
	Befriending	6
	Peer support	2
	Mentoring	1
Primary method of service delivery		
	Face-to-face	5
	Telephone	3
	Mixed (face-to-face and telephone)	1

5.4.2 Service operational similarities and differences

The length of time the services had been operating ranged from between one and ten years (Table 10). However, most commonly managers reported that their services were approximately five years old. Another similarity was that mostly female carers used their services. Six of eight participants (one non-response) also reported the majority of their volunteers were female, with six of seven (two non-responses) reporting that most of the carers were female. Also, volunteers tended to be on average younger in age when compared to the carers (52.06 versus 59.25 years). One of the biggest differences between the services was the range in numbers of volunteers (2-25) and carers (3-150).

5.4.3 Length of support sessions

An area where the services varied greatly was length of time each volunteer mentoring session lasted. Session time varied from between ten minutes to two hours, with an average of 73 minutes. Most commonly, managers reported volunteer mentoring sessions lasted one or two hours. However, despite the disparity in individual session length, the service providers were almost unanimous (eight from nine) in commenting that there was no fixed length of time (in weeks or months) the intervention overall lasted and that "*...it is given as long as the carer needs it*". The befriending services offered most flexibility over session time and length, followed by peer support which offered a more structured approach. By contrast, the mentoring service was very structured about session time and limited contact to eight weeks.

5.4.4 Cost

Of the nine service managers and volunteer coordinators who took part, only four gave the cost of the intervention per hour. The remaining five were either reluctant to share this information (2) or said they did not know the cost (3). Costs ranged from £4.94 to £25 with an average of £15.39 per hour. The telephone support intervention had the lowest cost per hour at £4.94. This is much less than the £58 to £120 per hour for befriending interventions in general reported by Knapp et al. (2013), but closer to the figure quoted by Poole (2010) of £20 per hour specifically for befriending of isolated older people. However, due to the small number of responses to this questions and a lack of verification of the responses given, caution is needed in interpreting the results here.

Table 10. Service operational details

Support type (location)	**Length of time services had been operating (years)**	**Length of time sessions last (minutes)** (average where a range of ages was given)	**Length of time volunteer mentoring lasts (weeks)**	**Cost of the service (£ per hour of support)**	**Volunteers per service**	**'Typical' volunteer in terms of age (years) and gender** (average where a range of ages was given)	**Carers of people with dementia receiving the service**	**'Typical' carer in terms of age and gender** (average where a range of ages was given)
Telephone befriending (Leicestershire)	5	120	As long as required by the carer	-	10	50-70 (60) and female	18	60-80 (70); 75% female
Face-to-face befriending (North Yorkshire)	-	120	As long as required by the carer	£12.50	6	16-65 and female (40.5)	3	64-84 (74); 66% female
Face-to-face mentoring (London)	5	60	12	-	25	-	24	-
Face-to-face and telephone Peer support (Kent)	10	10-60 (35)	As long as required by the carer	£25	2	40-70 (55) and mostly female	150	60 – 80 (70); mostly female
Face-to-face befriending (Kent)	8	60	As long as required by the carer	-	6	60 years old or over and female	10	-

Telephone peer support (Sussex)	*2*	*30-60 (45)*	*As long as required by the carer*	*-*	*-*	*Over 50 and female*	*30*	*Over 60; mostly female*
Telephone befriending (Kent)	6	15-60 (37.5)	As long as required by the carer	£4.94	12	Over 45 and mostly female (75%)	6	Over 45; mostly female
Face-to-face befriending (London)	1	60	As long as required by the carer	£19.12	15	22 to 70 (46) years old. Gender is equally mixed	13	70—90 (80); 95% female
Face-to-face befriending (South Yorkshire)	2.50	120	As long as required by the carer	-	10	Over 60. Gender is equally mixed	10	70-80 (75); equal numbers of males and females.
Average	**4.90 years**	**73.05 minutes**	**-**	**£15.39**	**10.75**	**52.06 years old. 6 of 8 participants reported mostly female volunteers**	**29.33**	**59.25 years old. 6 from 7 reported mostly female carers accessing the service**
Range	**1 - 10**	**10 - 120**	**-**	**£4.94 - £25**	**2 - 25**	**16 - 70**	**3 - 150**	**45 - 80**
Median	**5**	**60**	**-**	**£15.81**	**10**	**52.5**	**13**	**70**
Mode	**5**	**Bimodal – 60 and 120**	**-**	**N/A**	**Bimodal – 6 and 10**	**60**	**10**	**70**

5.4.5 Challenges

Two managers suggested that matching volunteers to carers was an issue for them, "(difficulty in) *finding suitable volunteers for the role to match* (with) *the individual carers.*" Another challenge was raising funds and having adequate resources, mentioned as an issue by two managers. This was said to prevent service growth, "*We are not funded for the service and so we are not able to grow*" and "*Budgeting and raising funds has been difficult*".

5.4.6 Aims of the services

Four primary aims common among most of the services were identified. Firstly, reducing social isolation and improving social integration were seen as primary aims by six of the nine services. One volunteer coordinator commented, "*...it's all about social integration and getting people involved.*" This was closely followed by reducing loneliness. Four managers specifically mentioned loneliness, whilst a further four highlighted ways in which loneliness could be reduced, for example "*... someone who is there just for them* (carers), *to bring friendship, mutual interests, someone to talk to and take an interest in their well-being.*"

Third, the provision of emotional support by volunteers for carers was highlighted as a key component of volunteer mentoring by five managers. Examples include, "*...carers also have the benefit of receiving emotional support and an increase in social contact*" and ways in which emotional support may be received, "*...give them* (carers) *a listening ear for a general chat or to talk about deeper feelings and issues.*"

Finally, providing advice and advocacy was perceived as something which could be an integral part of a volunteer mentoring, for example "*...to help them* (carers) *access services and financial entitlements, assist them with housing problems, make calls on their behalf, etc...*" and "*...it also helps people tap into other resources they may not have known about.*" It is clear from this that the services, whilst offering volunteer mentoring in different formats, in general, have similar aims and are seeking similar outcomes for carers.

5.4.7 Volunteers

The following section concerns the volunteers who delivered the volunteer mentoring interventions. It focuses on how they were recruited, supported and the relationships they were perceived to form with carers. An overview is presented in Figure 2.

5.4.7.1 Training and supervision

All nine managers and volunteer coordinators surveyed offered new volunteers training, but the type of training given and the length of time taken for completion varied. Specifically, training in safeguarding (3), developing boundaries (2) and vulnerable adult protection (2) were most commonly mentioned. Two managers stated that volunteers are given the opportunity to discuss further training needs in their monthly supervision.

Seven of the nine services offered their volunteers some form of supervision. Most commonly this was conducted individually with the service manager or volunteer coordinator; however two services held monthly group supervision which included all volunteers. Further, two services offered volunteers supervision by telephone or through email contact. One service suggested that volunteers receive emotional support as part of the "*supervision process*". The two services which did not offer supervision to volunteers were telephone befriending and peer support services.

5.4.7.2 Prior caring experience

One of the nine managers (face-to-face befriending service) reported that prior caring experience was essential for volunteers. A further three managers (face-to-face mentoring, telephone befriending and telephone peer support) commented it was preferable, but not a necessity if it is felt the volunteer is suitable for the role. This was highlighted by two managers who stated that "*They do need the right attitude for it and are coming into it for the right reasons*" and "*Prior caring experience is not essential as long as they have an appreciation for what carers do*". The final five managers responded that no previous caring experience is required for volunteers.

5.4.7.3 Recruitment

Recruiting volunteers was undertaken in a variety of ways. The most common and successful methods were local advertising through leaflet drops to General Practitioner (GP) surgeries and community organisations such as carers' centres (4). Also, word of mouth (4) was another way in which people would hear about the services and make contact. Other avenues of recruitment included the use of websites such as 'Do-It.org.uk', holding events, mail outs of newsletters and contacting carers who have previously used the service. Volunteers were recruited informally and a great deal of effort goes into advertising volunteer vacancies within local communities.

Many services reported sharing similar challenges with the recruitment and retention of volunteers, for example "*...the volunteers drop out. It is very hit and miss with the volunteers*".

5.4.7.4 Reasons for volunteering

Volunteer managers and coordinators suggested there were a number of reasons volunteers may decide to give their time. Four managers highlighted the volunteers' desire to help others, whether it was to pass on knowledge from their own caring experiences or giving carers the opportunity to talk about and share their problems, "*Some* (volunteers) *have had the service themselves, so know how much it can help to have someone to talk to*". A further two managers talked about how it gives volunteers the chance for social interaction "*...the volunteers themselves benefit from the social interaction*" or it can help with increasing self-confidence or reducing loneliness of former carers, "*One of the volunteers had severe depression and it helped him gain back confidence so he could work*". Finally one manager suggested it was a good opportunity for volunteers to gain experience and help them back into paid employment, "*...recently we have been getting younger volunteers who want to use it for their CV to get back into work*".

5.4.7.5 Friendships

Eight of the nine managers indicated that friendships develop between volunteers and carers, with only one commenting that it is not encouraged, "*...we do not encourage this. Once the mentoring relationship is over the mentor doesn't see the carer again.*" Of the remaining eight, two said that it does happen but that it is not encouraged. They also insisted that boundaries are needed. The final six suggested friendships develop naturally over time and carers and volunteers continue to see each other after the intervention has ended.

5.4.1 Carers

Content analysis suggested three main topic areas in the responses regarding carers. These were carer recruitment to the services, the importance of matching carers with volunteers and the reasons for carer withdrawal from the intervention.

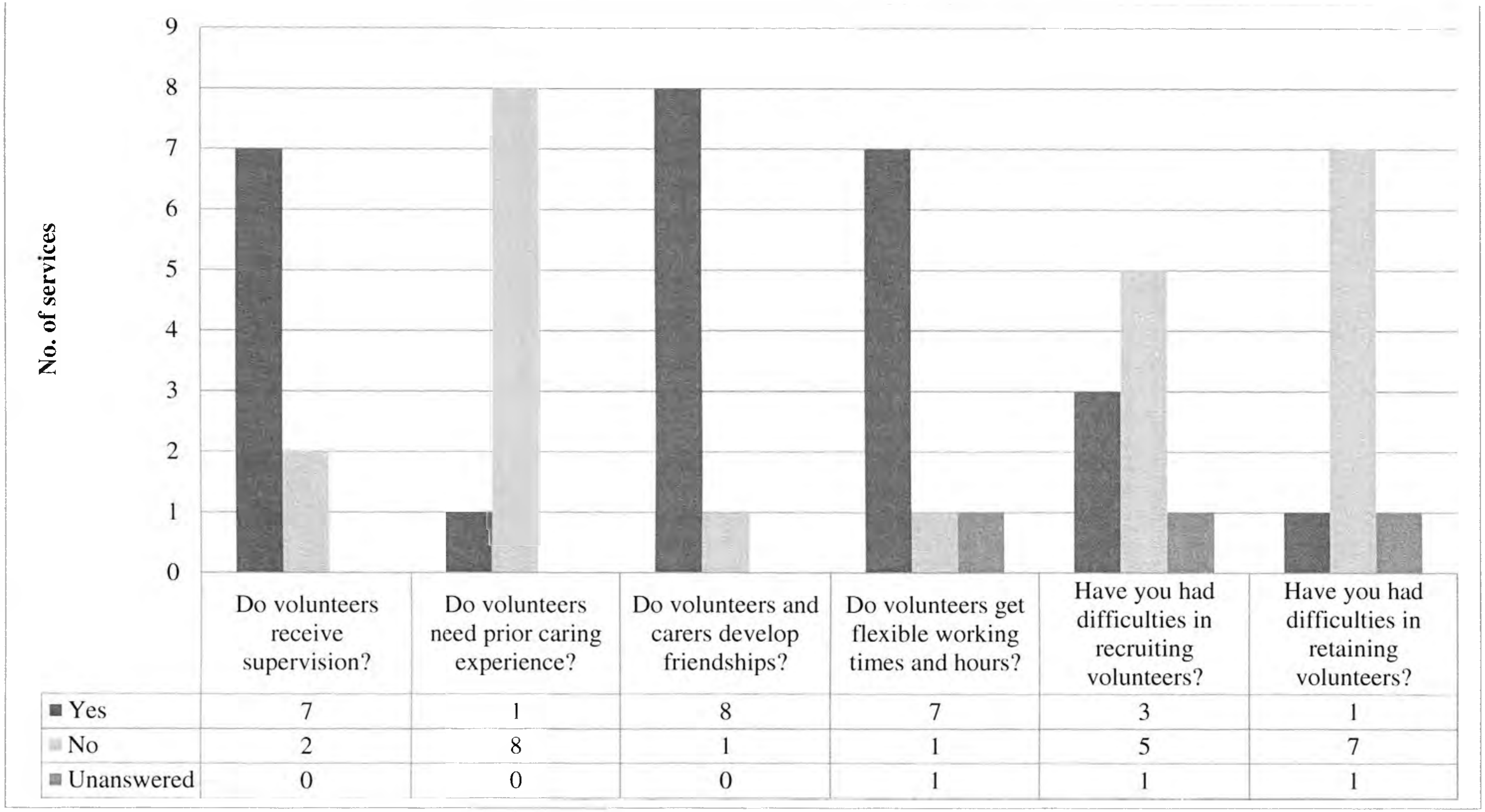
5.4.1.1 Recruitment

It was clear that carers were recruited in many of the same ways as volunteers, such as leaflet drops and through word of mouth. However, the importance of interdisciplinary networking was seen as essential to the flow of new referrals, with one volunteer-coordinator commenting "*...professionals who mention the service to carers*" boosted self-referrals. This was discussed by six managers and volunteer coordinators. Often these referrals from professionals came from social services (6) and district and Admiral Nurses (3). Only one manager mentioned obtaining referrals from GP surgeries. Managers and volunteer coordinators appear to rely heavily on referrals from other professionals for the recruitment of carers, which may have implications for whether the carers who are most likely to use the service are being identified.

Almost half of respondents reported difficulties with recruiting carers to the service. This could suggest ambivalence for carers in accessing the service or carers have difficulty in accessing and finding out about the services.

5.4.1.1 Matching

Two managers indicated that matching does not take place between carers and volunteers prior to the first visit. Of the remaining seven, five explained that matching is important, vital or essential, for example "*...this is really important. There is an initial assessment and carers and volunteers are matched on having similar interests and similar outlooks on life*" and "*It is of prime importance to match the volunteer to the carer*". A number of different reasons



	Do volunteers receive supervision?	Do volunteers need prior caring experience?	Do volunteers and carers develop friendships?	Do volunteers get flexible working times and hours?	Have you had difficulties in recruiting volunteers?	Have you had difficulties in retaining volunteers?
■ Yes	7	1	8	7	3	1
■ No	2	8	1	1	5	7
■ Unanswered	0	0	0	1	1	1

Figure 2. Volunteer recruitment, support and the relationships they likely form with carers

for matching were highlighted, including being able to build trust, help form links and due to people's personalities and individual requirements, " *I see this as vitally important as some carers are quite content with a good gossip while others will need someone who is willing to listen while they pour their heart out*". Further, five managers emphasised that carers will often ask for a volunteer of the same gender, "*some carers want to speak to volunteers of the same gender only. It's quite common for females to request females only*" and "*females tend to want female befrienders*". However, one manager indicated that matching occurs across a wide number of demographics, "*Factors for matching include,* (a) *carer's personality, what they are looking for from the mentoring service so that a volunteer with that experience can be allocated to them,* (also) *race, ethnicity, age, sex of carer*".

Whist matching was seen as important, it not clear if managers are relating its use to any background or theory. Two managers and volunteer coordinators explained they usually go with their experience in knowing what works well, "*There is no theory just a gut feeling after many years of working with volunteers about what relationships will work and what won't*" and "*There is no theory behind it, I just have a feeling who will go well together…who is good together, it naturally happened.*"

5.4.1.2 Carer withdrawal from the service

According to the participants, the intervention normally comes to a natural end with carers very rarely withdrawing from the intervention. Most commonly managers reported that this occurs when the person with dementia has gone into residential care, died or the carer feels they no longer need the support, with one manager explaining, "*If the PWD* (person with dementia) *died, has gone into residential care or they* (the carer) *feel they no longer need it*". However, one manager of a telephone befriending service explained how sometimes carers do not have the time to receive the support, "*A couple of people have dropped out because they said they sometimes found it annoying to stop what they were doing and answer the phone when their lives are so busy anyway*". Only one manager indicated carers commonly withdraw from the (face-to-face befriending) intervention "*regularly, mostly due to their loved one having to go into full time nursing care or dying*".

5.5 Discussion

This survey aimed to understand the differences and similarities between the various types of volunteer mentoring services. These service aims were to reduce social isolation, reduce loneliness, provide emotional support and give advice and advocacy. These are largely in line with English government policy regarding increasing emotional and social support for carers of people with dementia (Chapter Three).

One of the key findings of the survey was the disparity in service managers' views between matching and volunteers' prior caring experience. Matching carers and volunteers was described as important by most of the services. However, experiential similarity was not seen as important by the majority of managers.

The findings will now be discussed in relation to the research questions.

5.5.1 Research question 1: What are the similarities and differences between the services?

The heavy weighting of befriending services over other types of support (peer support or mentoring) made it difficult to draw conclusions which can be adequately applied to all three. It was expected that the importance of experiential similarity would differ between service type. However, only one befriending service described this as essential. By definition peer support implies experiential similarity will form an important part of the support process, as previously described by Sherman et al. (2004):

> "*…someone who has faced the same significant challenges as the support recipient, (and) serves as a mentor to that individual*".

Further, prior experience of the condition or caring role (depending on the population the service caters for) has previously been documented as a key aspect to peer support (Pillemer & Suiter, 2002), which makes this a surprising finding.

Six of the nine participants reported most of the carers accessing their services were female. This is in line with previous research reporting that the majority of carers accessing social support services are female (Coe & Neufeld, 1999; Siriopoulos et al. 1999).

In order to focus this discussion, only support which is (primarily) face-to-face will be investigated further in this PhD research. Face-to-face support appears to be more common and was the primary mode of administration in the studies in the systematic review. (Chapter Four) and the type of support offered by the services here (six face-to-face versus three telephone).

5.5.2 Research question 2: What are the range outcomes for carers and volunteers the services aim to achieve?

5.5.2.1 Carers

The central aims of these services were to increase social integration, reduce loneliness, offer emotional support and give advice and advocacy for carers. It is interesting to find that a primary outcome of these services is to provide emotional support to carers, yet the systematic review (Chapter Four) showed both peer support and befriending offer limited benefits for reducing mental health issues for carers. Given that the little available research (Pillemer & Suitor, 2002; Charlesworth et al. 2008) does not support the provision of emotional support by volunteers, further investigation is needed. However, research into the impact of volunteer mentoring for other groups, such as people with enduring mental illnesses (Dennis et al. 2009; Harris, 2006) or carers of people with other conditions (Greenwood & Habibi, 2013; Veith et al. 2006), has shown that emotional support is highly valued and can often lead to improved mental and physical health.

5.5.2.2 Volunteers

Previous research has highlighted reciprocity and mutuality as important aspects in the development of successful volunteer mentoring relationships (Andrews et al. 2003; Lester et al. 2012). Therefore it was important to understand how service managers and volunteer coordinators view the development of volunteer mentoring relationships. Service managers regarded altruism as an important reason why people become volunteer mentors, for example former carers now wanting to help others by passing on knowledge and experiences. This could also be an example of former carers, as Larkin (2009) described: 'constructing a life post-caring'. This was described by one service manager who talked about how two former carers (one with depression and one with loneliness) were volunteering as a means of helping themselves build social connections. The benefits of volunteering generally were described in Chapter Three, but given the lack of evidence for the impact of volunteer mentoring on volunteers (Chapter Four), this is a starting point in understanding the potential benefits for former carers. Further still, nearly all of the service managers talked about how friendships do occur between carers and volunteers. This could potentially suggest the development of mutually beneficial relationships is a reason for why people volunteer. However, this needs further exploration.

The focus of the services is on providing the best possible experiences for the carers, whilst offering varied support to volunteers. However, understanding the experiences of volunteers (both positive and negative) and in particular on former carers could offer insight into any mutually beneficial and reciprocal relationships which occur. This could have further implications for those running the services, in terms of volunteer recruitment and retention.

5.5.3 Research question 3: What roles do experiential similarity and matching have in the development of volunteer mentoring relationships?

5.5.3.1 Experiential similarity

Prior caring experience for volunteers was not seen as essential by these participants, despite previous research suggesting this might be important. The systematic review (Chapter Four) highlighted how carers value the experiential similarity of the volunteers, which fits with previous research indicating the value of homophily in the informal networks of carers of people with dementia. For example, Pillemer and Suitor (1996) showed how carers who were in contact with other carers in similar situations had lower levels of depression. Other research focusing on carers of people with dementia has also shown the value of experiential similarity in deepening trust and making it easier to discuss difficult topics (Suitor et al. 1995; Greenwood et al. 2013; Greenwood & Habibi, 2014). Exploring the difference in findings from the systematic review and this survey regarding experiential similarity is important. If the findings from this PhD research (Chapter Seven) support those from the systematic review (Chapter Four), it will give service managers an opportunity to review their volunteer recruitment and matching procedures.

5.5.3.2 Matching

The use of matching has its basis in Homophily Theory (Suitor et al. 1995; Thoits, 1986), in that people with similar backgrounds are likely to form stronger ties (Pillemer & Suitor, 2002). More specifically, it has been shown that successful volunteer mentoring relationships depend on matching the volunteer to the support recipient in other populations (Casiday et al. 2008). The findings of this survey showed matching of carers and volunteers was seen as very important to the development of a strong and long lasting volunteer mentoring relationship. However, matches often take place based on the feelings or 'gut instincts' of the managers or volunteer coordinators, rather than being theory driven. As with experiential similarity, this finding differs from those of the systematic review. The main area of matching found in the review was based on experiential similarity, matching based on other demographic or 'structural' similarities (Andrews et al. 2003; Suitor et al. 1995) was not found to increase the number or length of visits between peer supporters and carers (Sabir et al. 2003). However, only one study was found regarding prior matching of carers and volunteers and the results need interpreting with caution due to the limited evidence. Given these differing findings, further understanding of the processes of how volunteers and carers form mutually beneficial relationships is needed.

5.5.4 Relation of the survey findings to the theoretical perspectives of the thesis

One of the most important findings from this survey is that service managers and volunteer coordinators were not matching carers and volunteers based on any obvious theoretical perspectives. It was mentioned how matching often takes place on 'gut instinct' or knowing who will work well together based on their prior experience of running the service. It appears from their focus on matching based on structural similarities and common interests, as opposed to experiential similarity of the volunteers, that they believed that matching on this basis has had prior success. However, as previously described, research has often shown the importance of experiential similarity in the formation of trusting relationships of a reciprocal nature. Further research is needed here to explore carers' and volunteers' perspectives of the experiences of what makes for successful volunteer mentoring relationships.

5.5.5 Relation of survey findings to English policy

The importance of developing befriending services for carers has been recognised by the English government as an area for development in order to "*avoid isolation and loss of connectivity with family, friends and place*" (HM Government, 2010, p. 47). In addition, the Conservative Government's Big Society policy (Conservative Party, 2010) aims to develop a society where people are coming together to help improve the lives of themselves and the communities in which they live. The findings of this survey would suggest the aims of the services surveyed are largely in line with these objectives. For example, involving people in volunteering, increasing social integration and reducing loneliness were frequently mentioned by service managers and volunteer coordinators. These objectives are also reported in policy surrounding the specific development of volunteer mentoring services for carers of people with dementia (Chapter Three), highlighted by the National Dementia Strategy (DoH, 2009) which suggested support for carers should "*...provide practical and emotional support, reduce social isolation and promote self-care*" (p. 41). However, it was also stated that support from peers should be the primary method of service delivery, with the rationale being based around the perceived benefits of talking to others in similar situations to gain emotional support and advice. This is an area the services surveyed were generally not actively pursuing, instead focusing on matching based on the previously mentioned structural similarities.

5.5.6 Limitations

The main limitation of this survey is the small number of service managers and volunteer coordinators who responded. This limits the strength of conclusions which can be drawn. However, those that did respond explored similar topics. The main aim of this survey was to gain a clearer understanding of the outcomes these services aim to offer and how that relates to the systematic review (Chapter Four). Together they provide a strong basis for further more in-depth exploration of volunteer mentoring on carers and volunteers.

Another limitation is the mixture of face-to-face and telephone support. It could be that one offers better outcomes compared to the other, however studies investigating either face-to-face (Pillemer & Suitor, 2002) or telephone (Stewart et al. 2006) volunteer mentoring interventions have reported positive findings. It was shown that the telephone services here reported lower costs per carer accessing the service. However, too few provided costs to draw firm conclusions.

A challenge of this survey was recruiting service managers. In order to do this, a variety of ways in which they could complete the questionnaire was offered, including over the telephone, post or email. The majority emailed completed questionnaires. Subsequently, there were large variations in detail and quality of data collected, with some managers leaving sections blank or writing very brief responses which offered little information. This could have led to important information not being identified and could potentially affect the strength of the conclusions drawn.

A further limitation of this survey was the method of data analysis. Using content analysis by counting frequencies leaves the possibility of important data being missed or classed as less important if occurring less frequently in the data (Prasad, 2008).

5.6 Conclusions

The services investigated here aimed to increase social integration, reduce loneliness, offer emotional support and give advice and advocacy. Whilst they operate differently in terms of mode of delivery, the services had similar aims and goals in common. Matching the volunteers to carers based on structural similarities was seen as important and was often based on similar backgrounds, interests and hobbies. However, it was also a decision taken by managers or volunteer coordinators based on their feelings of which volunteers and carers were likely to form relationships. The lack of need of experiential similarity of volunteers was not supported by previous research, understanding this difference was important for investigating the services' effectiveness. It also highlighted that managers perceived potential benefits for former carers who were now volunteering. The findings of this survey, coupled with those from the systematic review (Chapter Four), have helped to develop the research questions for Phase Two of this research.

Next, the methods of Phase Two are described in detail. This is followed by the findings of Phase Two (Chapter Seven) and the overall discussion of this research (Chapter Eight).

6 Chapter Six: Methodology of Phase Two – a mixed methods investigation

6.1 Introduction

This chapter marks the beginning of Phase Two of this research and explains its methodology. It follows from Phase One which included a systematic review (Chapter Four) and survey of volunteer mentoring services (Chapter Five). The findings from Phase One shaped the research design of Phase Two.

In the systematic review of the literature (Chapter Four), differing findings for the effectiveness of volunteer mentoring services between qualitative and quantitative research were highlighted, making these divergent findings an important area for investigation. Similarly, differing opinions between service managers and volunteer co-ordinators were reported in the survey. These contradictory findings and lack of evidence for the effectiveness of volunteer mentoring for carers of people with dementia and volunteers was of concern, given the English government's policy of promoting the development of these services (Department of Health, 2009).

The theoretical perspectives Homophily Theory and SET (section 3.5) continued to shape this phase. Homophily Theory has been chosen by drawing on evidence regarding the importance of experiential similarity, SET has been chosen in response to the evidence suggesting that volunteers are more likely to continue volunteering if the relationships are mutually beneficial. This research investigates volunteer mentoring at the service user level and is an in-depth exploration of the impact of volunteer mentoring on the carers and volunteers involved in these services. A mixed methods approach was chosen to answer the research questions of Phase Two which investigated both the impact and experiences of carers and volunteers. This phase aimed to answer research questions 2, 3, 4 and 5 of the thesis, documented in section 1.2:

2. What do the processes underlying volunteer mentoring involve?
3. What types of relationships do carers of people with dementia and volunteers form?
4. What is the evidence for the impact of volunteer mentoring for carers of people with dementia?

5. What are the volunteers' experiences and perceptions of volunteer mentoring?

The chapter starts by describing mixed methods research and the philosophical underpinnings of Phase Two. The research design is then described, followed by a detailed presentation of the methods used in both the quantitative and qualitative phases. The chapter ends by exploring ethical considerations of this research and the conclusions.

6.2 Mixed methods as a methodology

The research methodology of Phase Two is guided by the researcher's philosophical assumptions (ontology and epistemology, Guba 1990), that there are both singular and multiple realities. This, along with the belief of the primary importance of the research questions gives rise to pragmatism underpinning the research, along with recognising that post-positivist and constructivist approaches will be adopted for quantitative and qualitative data collection respectively.

6.2.1 Mixed methods research

There have been numerous definitions of mixed methods research since it became more accepted as a research design in the 1980's (Burke Johnson et al. 2007). It is now regarded as the third research paradigm, with Burke Johnson et al. (2007, p. 129) arguing that it:

> "*...recognizes the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative, complete, balanced, and useful research results*".

Burke Johnson & Onwuegbuzie (2004) also state that mixed methods studies use inductive reasoning (associated with qualitative research and develops general conclusions based on the exploration of how individuals experience and perceive the world around them); deductive reasoning (associated with quantitative research and uses a top-down process that tests general premises though a series of steps to reach specific conclusions) and abuductive reasoning (a process that values both deductive and inductive approaches but relies principally on the expertise, experience, and intuition of researchers). Highlighting the lack of clear consensus amongst experts, Creswell and Plano Clark (2011) suggested that a definition of mixed methods research should incorporate a number of different core characteristics based on different viewpoints. They suggest six key components which defines mixed methods research:

1. Collects and analyses both quantitative and qualitative data
2. Mixes or integrates the two forms of data by combining them concurrently, sequentially or embedding one within the other
3. Gives priority to one or both forms of data
4. Uses these procedures in a single study
5. Frames these procedures within philosophical worldviews and theoretical lenses
6. Combines the procedures into research designs that direct the plan for conducting the study

More simply, Tashakkori and Teddlie (1998, p. xi) define mixed methods research as combining "*qualitative and quantitative approaches in the methodology of a study*". This view is largely shared by Burke Johnson et al. (2007, p. 119), who listed 19 different definitions from different experts in the field. Based on their analysis of all 19 definitions, they developed their own:

> "*Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.*"

It is this clear and concise definition which will be adopted in this thesis when referring to mixed methods.

Now that mixed methods research has been defined, it is important to differentiate between the terms mixed methods and multiple methods, as they are often used interchangeably despite incorporating different research designs (Hesse-Biber, 2010, p. 3). For example, Morse (2010, p. 340) argued:

> "*...multiple methods design consists of two or more studies using different methods, which address the same research question*" and that each part is "*...publishable as a stand-alone article*".

This shows that no 'mixing' occurs at any stage of a multiple methods study and sets it apart from a mixed methods design where the integration of qualitative and quantitative data is an essential component. Tashakkori and Teddlie (1998) suggest that the term 'mixed model' is often more appropriate than 'mixed methods' in some studies due to mixing occurring at all stages of the research, as opposed to different types of data collected separately and then mixed or integrated during the final data analysis).

6.2.2 History of mixed methods research

The basis for mixed methods thinking can be traced back to the 18th Century to the time of Giambattista Vico (1668-1744) who relied on multiple approaches to gaining knowledge (Burke Johnson & Gray, 2010). However, it was Campbell and Fiske (1959) who first introduced the idea of triangulation in quantitative research to establish construct validity of psychological traits, with their 'multitrait-multimethod matrix'. This was referred to as 'multi operationalism' (the use of more than one method of measurement in a single research study). Although in the PhD research triangulation was used with different quantitative methods in the same study, it has since been used in mixed methods research (Creswell and Plano Clark, 2011). Triangulation of data were next reported in a methods book by Webb and colleagues in 1966 (Burke Johnson & Gray, 2010) and later developed in the 1970's in order to be used as a way of combining qualitative and quantitative methods in a single study (Denzin, 1970).

Mixed methods research first started appearing in published articles during the 1980's (Niglas, 2010). For example, Creswell and Plano Clark (2011) highlight the work by Patton in 1980 which suggests the use of 'methodological mixes' for experimental and naturalistic designs. Later, Cook (1985) put forward the idea of critical multiplism, which suggests the use of different methods to gain different insights. However, it was only during the late 1990's with the publication of Tashakkori and Teddlie's book 'Mixed Methodology: Combining Qualitative and Quantitative Approaches' (1998) that mixed methods research started to develop into a method of inquiry in its own right (Creswell, 2011).

Creswell and Plano Clark (2006) developed a historical overview of recent mixed methods history which encompasses four often overlapping time periods. This overview is important here as it will be referred back to when discussing the philosophical foundations for mixing methods. Firstly, it is argued that a 'formative period' occurs (1950s through to the 1980s), in which interest began growing over the use of more than one method in a study. Next is the 'paradigm debate period' (1980s through to the late 1990s), this debate was concerned with whether paradigms could be combined, with some arguing mixed methods research was untenable. Thirdly, Creswell and Plano Clark argue that there is a 'procedural development period' (1980s through to 2000s), during which attention focused on designing and undertaking mixed methods research. Finally, the 'advocacy as separate design period' (2000s to present) highlights the call for mixed methods research to be considered the third paradigm.

Arguably the most important periods in the history of mixed methods research mentioned above, was the 'paradigm debate period' (Creswell & Plano Clark, 2006) or the 'paradigm wars' (Gage, 1989). Despite the progress in the development of mixed methods research during the 1970's and 1980's, during this period there was a great deal of discussion as to whether or not it was possible to combine quantitative and qualitative methods in a single study due to diverging philosophical assumptions (Creswell and Plano Clark, 2011). To try and circumvent the controversies and debates over the use of multiple paradigms, Rossman and Wilson (1985) suggested that pragmatism should be used in mixed methods research. By using pragmatism as a paradigm it would be possible to combine quantitative and qualitative methods. Pragmatism is viewed as both the foundation and best paradigm for using mixed methods research (Tashakkori & Teddlie, 2003). Despite the development of pragmatism, the debate over paradigms continues with some researchers adamant that paradigms cannot be mixed (Creswell, 2011), however others argue that we are beyond this debate and free to use mixed methods in research (Sale et al. 2002).

More recently, Greene (2008) argued that not only do mixed method approaches have the potential to become a distinctive methodology within the social sciences, but that it "*offers deep and potentially inspirational and catalytic opportunities to meaningfully engage with the differences that matter in today's troubled world*" (p. 20). With this, it is apparent that the future of mixed methods research is one which is still developing, but it is already seen by many as the third paradigm (Burke Johnson et al. 2007; Hesse-Biber & Burke Johnson, 2013).

6.2.3 Justifications for mixed methods

It is important to be thorough in explaining the reasons for mixing methods, as researchers have been indiscriminately mixing methods without highlighting defensible reasons for doing so (Greene et al. 1989). Five reasons for why researchers should use mixed methods:

triangulation; complementarity; development; initiation and expansion were proposed by Green et al. (1989). These are explained further in Table 11.

Table 11. Reasons for mixing methods (Green et al. 1989).

Triangulation	Seeks convergence, corroboration, and correspondence of results from the different methods.
Complementarity	Seeks elaboration, enhancement, illustration, and clarification of the results from one method with the results from the other method.
Development	Seeks to use the results from one method to help develop or inform the other method, where development is broadly construed to include sampling and implementation, as well as measurement decisions.
Initiation	Seeks the discovery of paradox and contradiction, new perspectives of frameworks, the recasting of questions or results from one method with questions or results from the other method.
Expansion	Seeks to extend the breadth and range of inquiry by using different methods for different inquiry components.

The reasoning for the current research adopting mixed methods is to use triangulation to increase the reliability and credibility of the results, and to use complementarity to seek enhancement and clarification of the findings of one method with the other. This framework for mixing methods was built upon by Bryman (2006), who list 16 reasons for mixing methods. Of the 16, triangulation and complementarity are explicitly mentioned, but some others which are particularly relevant to the current research are highlighted here. Firstly Bryman talks about completeness, in that a more comprehensive account of the area under investigation can be achieved through using both quantitative and qualitative methods. Finally, 'explanation' in that the qualitative phase will be used to explore and explain results from the quantitative phase.

By using a mixed methods approach, it was possible to confirm and corroborate the quantitative findings by using interviews with carers. This also allowed for the different types of data to be combined to allow for a more comprehensive understanding of how volunteer mentoring impacts on carers. Overall, these reasons for mixing methods have been highlighted by Mertens and Hesse-Biber (2012) who stated that:

> *"Quantitative and qualitative data can be mixed for the purpose of illustrating a more complete understanding of the phenomenon being studied" (p. 78).*

6.2.4 Mixed methods research with carers of people with dementia

Mixed methods research is commonly used in health services research in the UK and is often used to answer complex questions which may be insufficiently answered through quantitative methods alone (O'Cathain et al. 2007).

There are examples of mixed methods research investigating interventions for carers of people with dementia. In a meta-analysis of psychosocial interventions, Brodaty et al. (2003) found that a number of controlled trials have been conducted with interventions for carers of people with dementia. It was shown that carer interventions have a modest but significant impact on mental health outcomes, burden and social support. Similar conclusions were drawn by Powell et al. (2008), suggesting that interventions can have a moderate effect on carer depression and stress. This shows quantitative methods are often used in carer research and that they are adequate for detecting changes over time in this population. However, using an exploratory triangulation design model, Stirling et al. (2010) investigated carers of people with dementia and their unmet need for services. They found that linking contextual information helped to inform the interpretation of the quantitative results. This was also shown by Petros (2012), who argued the use of mixed methods research for carers enabled the corroboration of quantitative and qualitative findings, to give a better understanding of the issues which affect older carers.

The findings above demonstrate the varied approaches adopted when researching intervention for carers of people with dementia. However, more specifically there have been multiple approaches used in investigating volunteer mentoring for carers of people with dementia. Studies involving carers of people with dementia and volunteer mentoring (as highlighted earlier in the systematic review, Chapter Four) by Charlesworth et al. (2008), Pillemer and Suitor (2002) and Sabir et al. (2003), were all primarily quantitative and found largely statistically insignificant results regarding outcomes for carers. However, the qualitative study by Stewart et al. (2006) highlighted how carers found that volunteer mentoring offered a positive experience. Given the contrasting findings between quantitative and qualitative results from the systematic review, the current research will seek to explore and identify reasons for these inconsistencies.

6.2.5 Pragmatic approach of Phase Two

Mixed methods research offers flexibility to use a combination of data collections methods which will best answer the research questions (Hesse-Biber, 2010). It has been argued that pragmatism is the most appropriate philosophical foundation for mixed methods research, as different research paradigms can be used to fully address the research problem (Creswell & Plano Clark, 2011). Pragmatism allows for both inductive ('bottom-up') and deductive reasoning ('top-down') (Creswell & Plano Clark, 2011). Sammons (2010) highlights that pragmatism uses both quantitative and qualitative methods. Therefore, pragmatism was used as the umbrella framework (Creswell & Plano Clark, 2011), with post-postivism used for the quantitative phase and constructivism for the qualitative phase.

The quantitative phase of the research was concerned with whether or not volunteer mentoring services offer improved outcomes for carers. Based on the findings from previous chapters (systematic review and the survey of service managers) this investigated mental health (depression and anxiety), loneliness and social inclusion. Initially a post-positivist world view was adopted. This paradigm, although it follows the same principles as positivism but allows for more interaction between research and participants (Willis, 2007), is best suited to quantitative methods as it places high value to experimental methods. This is largely due to the paradigms ontological view holding that "*there is one reality-one truth-that can be known within a certain level of probability*" (Mertens, 1998).

The quantitative phase was followed by the qualitative phase, where a constructivist epistemology was adopted. Creswell and Plano Clark (2011) document that constructivism is a 'bottom up' approach to shaping research, in that the individual perspectives of participants lead to much broader understandings. It is primarily used in qualitative research and emphasises the socially constructed nature of reality (Mertens, 2009). The qualitative phase sought to answer if and how volunteer mentoring works based on findings from the quantitative phase. During this phase volunteers were also interviewed using the same constructivist epistemology.

6.3 Mixed methods research design

The aim of this mixed methods research was to build upon the findings of previous chapters. In the systematic review (Chapter Four), differing findings for the effectiveness of mentoring services between qualitative and quantitative research were highlighted making this an important area to investigate. The main weighting was given to the quantitative phase which was then followed up with a qualitative phase to explore and confirm the results obtained. This has led to the use of a sequential explanatory design (Creswell & Plano Clark, 2011), which is explained in further detail below.

Based on the researchers ontological and epistemological beliefs, a sequential explanatory mixed methods design (Figure 3) was chosen (Creswell, et al. 2003; Creswell, 2009; Tashakkori & Teddlie, 1998). This design has both quantitative and qualitative phases, as shown in Figure 3. Priority was given to the quantitative methods in addressing the primary research questions, with the collection of qualitative data to help explain and explore the quantitative results (Morse, 1991, Creswell & Plano Clark, 2011).

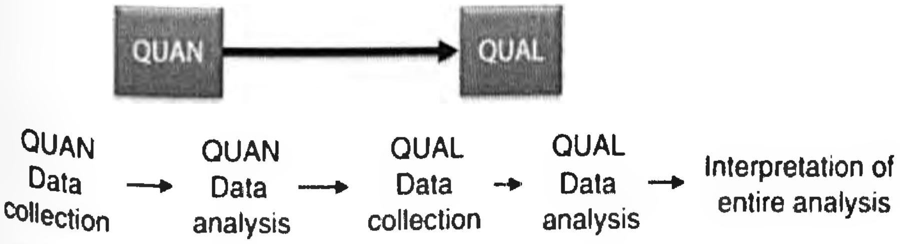


Figure 3. Sequential explanatory design (Creswell & Plano Clark, 2006).

The sequential explanatory design was judged as most appropriate due to the emphasis placed on the quantitative data and that being followed up with a qualitative phase. However, Creswell and Plano Clark (2011) list five other mixed methods designs which were considered when planning this element of the research. Firstly, the exploratory sequential design which starts with the collection of qualitative data phase (which is prioritised for answering the research questions) followed up by a quantitative data collection phase to test or generalise from the initial exploratory phase. Secondly, there is the convergent parallel design, which happens when researchers implement both quantitative and qualitative methods during the same phase. Thirdly, there is the embedded design, which occurs when quantitative and qualitative data are collected within a tradition quantitative or qualitative design. Forth, there is the transformative design, which frames the data within a transformative, theoretical framework that guides the methods decisions. Finally, there is the multiphase design, in which concurrent or sequential collection of data sets is conducted over multiple phases of a program of study.

6.4 Methods

6.4.1 Research questions

The research questions aim to provide a clear and comprehensive understanding of the processes involved with volunteer mentoring and to identify any outcomes.

1. What do the processes underlying volunteer mentoring involve?
2. What types of relationships do carers of people with dementia and volunteers form?
3. What is the evidence for the impact of volunteer mentoring for carers of people with dementia?
4. What are the volunteers' experiences and perceptions of volunteer mentoring?

6.4.2 Aims

1. To investigate the impact volunteer mentoring has on carers' mental health (quantitative scales).
2. To explore what aspects of volunteer mentoring are beneficial for some carers and less so for others (qualitative interviews).
3. To explore any positive and negative impacts on volunteer mentors (qualitative interviews).
4. To improve understanding of the processes underlying volunteer mentoring.
5. To investigate any differences between the different types of volunteer mentoring services (befriending and peer support).
6. To improve understanding of the relationships formed between carers and volunteers.

6.4.3 Setting

This research was initially planned to include only volunteer mentoring services from London and South East England. However, due to recruitment difficulties it was extended to volunteer mentoring services across England. In total, seven services took part in assisting with recruiting carers (Table 12) and five services assisted in recruiting volunteer mentors (Table 13). Two services were specifically for carers of people with dementia (South East England and Yorkshire) and five were for carers or older people in general, which carers of people with dementia were accessing.

Table 12. Location of services assisting in the recruitment of carers

	Service type	**Location**	**No. of information packs sent**
1	Befriending	London	30
2	Befriending	London	20
3	Befriending	East of England	10
4	Befriending	East Midlands	20
5	Befriending	Yorkshire	20
6	Befriending	South East England	10
7	Peer support	South East England	50
			Total - 160

Table 13. Location of services assisting in the recruitment of volunteer mentors

	Service type	**Location**	**No. of information packs sent**
1	Befriending	East Midlands	20
2	Befriending	East of England	10
3	Befriending	London	20
4	Befriending	Yorkshire	30
5	Peer support	South East England	20
			Total - 100

6.4.4 Service identification

Service identification and recruitment took place between February 2013 and September 2013. Prior to data collection a great deal of networking with services had already taken place. Initially, managers and volunteer coordinators who took part in the survey (Chapter Five) were contacted to determine if they were interested in helping to recruit carers and volunteers. All contacted services were asked if they knew of any other similar services in the area. When the list of services was exhausted, contact was made with other managers from those previously not contacted or those who had previously not responded to the survey (Chapter Five). Further services were identified through the internet searching. Service managers who agreed to take part were then sent an information letter (Appendix 14) with return form (Appendix 15) and a stamped addressed envelope (SAE). Those managers who were not contactable by telephone were either emailed or posted the information pack. The success of these methods of service recruitment varied, however those contacted by telephone generally showed greater interest in taking part. In total, 33 services were contacted, with seven agreeing to assist with recruitment of carers and five with recruiting volunteer mentors (Figure 4). Twelve services declined to take part and a further 16 did not respond to either the initial contact or follow up calls or letters.

6.4.5 Service recruitment

Service managers who had indicated they would assist with recruitment of participants were sent pre-stamped information packs to send to carers and volunteers. The number of information packs requested by managers ranged from 10 to 50 (the peer support service in South East England initially requested 30, but requested a further 20 after four months) (Table 13). Further to this, the researcher attended a carers' support group to explain who he was and the importance of the research. The researcher also met face-to-face or talked over the telephone with managers who requested further information about the research before deciding on whether to take part.

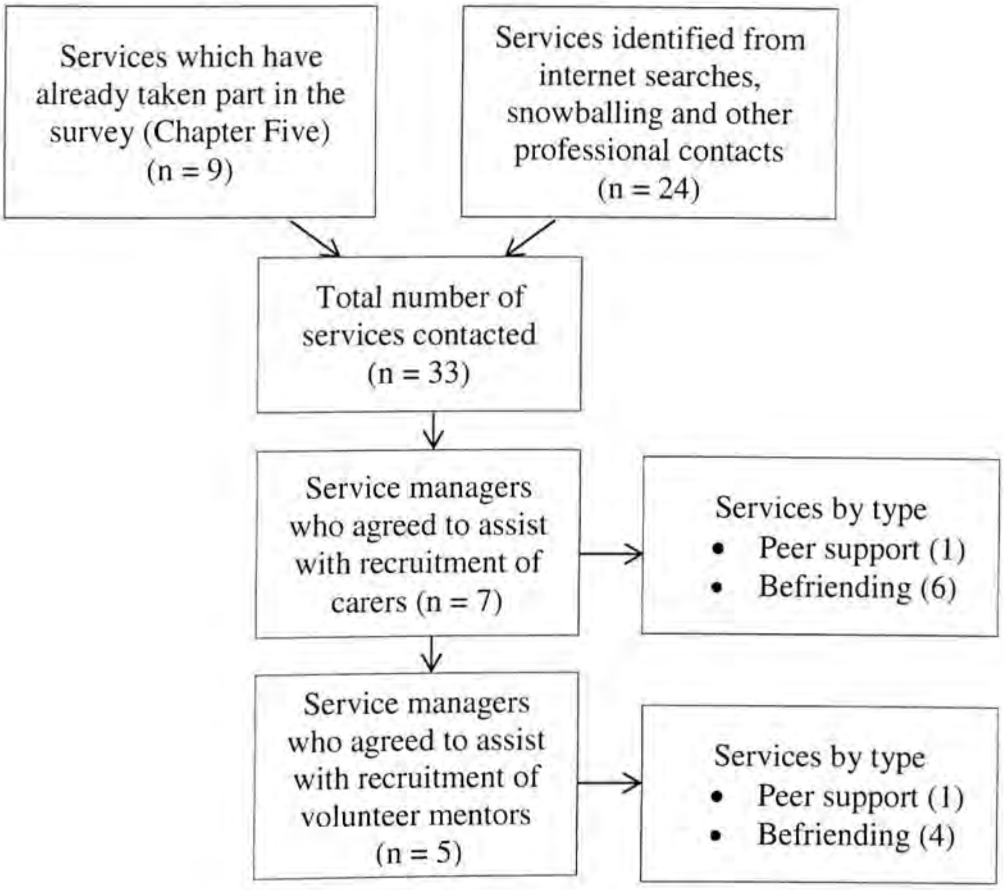


Figure 4. Flow diagram showing the recruitment of services.

6.5 Quantitative phase methods

This phase focused on carers of people with dementia who were receiving a volunteer befriending or peer support intervention. Volunteer mentors did not take part in this phase. This quantitative phase design is a longitudinal survey conducted over six months using validated questionnaires.

6.5.1 Participants

To take part, carers needed to be new to the befriending or peer support service and were in receipt of one-to-one support from volunteers. In most cases, carers and volunteers usually met face-to-face once per week, although there was often flexibility over this, in particular for those receiving befriending. There was no time limit on how long a carer could receive the befriending or peer support for any of the services. Nineteen carers were enrolled at baseline.

Retention was 100% at three month follow-up and 84% at six month follow-up (three carers withdrew from the study). This is in line with other studies involving carers of people with dementia which reported attrition as 18.5% (Goodman & Pynoos, 1990) and 19% (Charlesworth et al. 2008).

6.5.2 Inclusion criteria

Carers needed to be:

1. Caring for a person with dementia
2. Aged over 18 years
3. New to receiving volunteer mentoring upon enrolment into the research
4. Receiving a primarily face-to-face volunteer mentoring intervention

6.5.3 Exclusion criteria

Carers were excluded if they were:

1. Not caring for a person with dementia
2. They paid to receive volunteer mentoring

6.5.4 Sample size

The primary outcome measure was change in HADS-depression scores between baseline and six months follow-up. Due to the lack of research on volunteer mentoring for carers of people with dementia, defining an adequate effect size to enable sample size calculations was challenging. No Minimum Clinically Important Difference (MCID) has been established for the HADS in the population under examination. In total, five experts in the field of research (including four authors from the previously reported systematic review) were contacted to ask what they thought would be a clinically meaningful reduction in depression in HADS from baseline. No responses were received, therefore the significant reduction in depression score seen by Charlesworth et al. (2008) of two points on HADS between baseline and 15 months follow up (9.5%), was taken to calculate an effect size and for detecting a MCID. Due to the lack of previous research in this field, it was assumed that a standard deviation of 3.5, as calculated using a pooled SD from baseline and 15 months follow up from Charlesworth et al. (2008), would be a best estimate for the variation from the mean. Using a distribution-based approach (Norman et al. 2001) a Cohen's D calculation (Cohen, 1988), a 'medium' effect size of 0.57 was found (2 points change on HADS/3.5 standard deviations).

To estimate a sample size, the power analysis programme G*Power 3.1 was used (Faul et al. 2009) as it is commonly applied in social research (Faul et al. 2007). To achieve 80% power at the 5% significance (two-tailed) and assuming normal distribution, this research requires 25 participants. The level of statistical power was decided upon based on Cohen (1988), in which it was suggested that power of 80% (β = .20) should be a minimum. This also required fewer participants (compared to power of 95%) and allow for adequate use of resources and time. In order to account for loss to follow up, similar studies investigating peer support and befriending interventions for carers of people with dementia were examined. They reported attrition ranging from 18.5% (Goodman & Pynoos, 1990), 19% (Charlesworth et al. 2008) and 28% (Pillemer & Suitor, 2002). The highest level of reported attrition of 28% (Pillemer & Suitor, 2002) was used to calculate final sample sizes in order to be sure enough participants are recruited. Therefore, this research required the enrolment of 35 participants at baseline. Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS version 17) and the analysis conducted once all data collection was completed.

6.5.5 Recruitment procedure

Convenience sampling was selected to recruit carers. All carers had an equal chance of taking part due to service managers providing them with the research study details upon joining the service. Participants were recruited from either volunteer befriending or peer support services currently operating in southern or central England. Potential participants were given an information letter (Appendix 16) detailing what participation would involve, along with a return form (Appendix 15), and SAE. Once a carer had returned the form they were contacted by telephone to determine how best they would like to complete the questionnaires (by post or face-to-face).

6.5.6 Data collection

Quantitative data were collected at baseline, three months and six months between March 2013 and April 2014. After carers returned the appropriate forms, they were contacted to check they still wanted to participate and, if so, to arrange a suitable time to either meet face-to-face or over the telephone. Carers could either receive the questionnaires by post or the researcher would visit them at home. Five carers asked me to visit them. Reasons included having difficulty understanding questionnaires and difficulty completing forms. Carers were contacted again at three months and six months before the next set of questionnaires were due to be completed, to confirm they still wanted to take part and were still receiving the intervention. The questionnaires measured self-reported depression, loneliness and perceived social support. Full details of the questionnaires used are presented in section 6.6.8.

6.5.7 Data analysis

Both descriptive and inferential statistics were used. As this research used a repeated measures design (data were collected at three time points) and the data were ordinal, the non-parametric Friedman test (Friedman, 1937) was used. Post-hoc analysis was conducted using the Wilcoxon Signed-Rank test on significant results. To avoid type I error, the Bonferroni adjustment was calculated as 0.017 by dividing the pre-defined alpha level ($p = 0.05$) and dividing it by the three post hoc tests ($0.05/3 = 0.017$):

1. Baseline and three month follow up
2. Baseline and six month follow up
3. Three month follow up and six month follow up

A p value of less than 0.017 resulting from the post hoc tests was considered significant.

6.5.8 Quantitative measures

All participants taking part in this phase completed a questionnaire collecting demographic details such as age, gender, ethnicity and marital status (Appendix 17). This questionnaire also asked how long they had been caring for the person with dementia, how they were related to the person with dementia and the other support services they are currently receiving.

6.5.8.1 Depression and anxiety

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) (Appendix 18) was chosen to measure emotional distress. This scale was used in the Charlesworth et al. (2008) study which was included in the systematic review (Chapter Four). Originally, the HADS was intended for use for measuring levels of depression and anxiety in hospital settings (Zigmond & Snaith, 1983). However, it has since been used in the general population (Crawford et al. 2001) and in a variety of settings (Flint & Rifat, 2002; McCue et al. 2006). It has also been validated for use in older populations (60> years) for measuring depression and anxiety (Flint & Rifat, 2002) and been used when investigating depression and anxiety in carers of people with Alzheimer's disease (Charlesworth, et al. 2008; Mahoney et al. 2005).

This self-report questionnaire takes approximately two to five minutes to complete (Snaith, 2003) and requires participants to answer 14 questions (seven relating to depression and seven to anxiety). Participants rate themselves from zero (no distress) to three (maximum distress) with the maximum scores for each scale subsection being 21. The HADS Manual (Zigmond & Snaith, 1994) states that should be interpreted according to Table 14.

Table 14. Interpreting HADS scores. Taken from Zigmond & Snaith (1994).

Score	**Interpretation**
0-7	Normal
8-10	Mild
11-14	Moderate
15-21	Severe

Crawford et al. (2001) suggest using the cut-off of 11 or more on the scale as a way of identifying people with depression when the HADS is being used in the general population. They identified that 3.6% of the sample in their study would be classed as having depression which they argue fits with epidemiological studies of the prevalence of depression, as opposed to a score of eight or more in which 11.8% of people were classed as depressed. As with depression, Crawford et al. (2001) suggest using a cut-off of 11 or more when identifying people with anxiety, which identified 12.6% of the population as having either moderate or severe anxiety. Zigmond & Snaith (1983) and Bjelland et al. (2002) suggest using a cut-off of eight or more for identifying people with both depression and anxiety. However, the cut-off of 11 or more was used as described by Crawford et al. (2001) due to participants being selected from the general population and age as a demographic not seen as a variable which has an effect on HADS scores. Thus, when reporting the finding in Chapter Seven, carers with anxiety and depression would have achieved a score of 11 or more and those without a score of 10 or less.

Reliability. The internal consistency of the two subscales was established by Moorey et al. (1991), with Cronbach's alpha found to be 0.93 for the anxiety subscale and 0.90 for the depression subscale for people with cancer. However, Crawford et al. (2001) found a Cronbach's alpha of 0.82 for the anxiety subscale and 0.77 for the depression subscale in the general population. Whilst this is lower than that reported by Moorley et al. (1991), alpha coefficients of more than 0.70 indicate good reliability (Nunnally, 1978).

Validity. The construct validity of the HADS, defined as "*the degree to which a test measures what it claims, or purports, to be measuring*" (Cronbach & Meehl, 1995), was described by Bjelland et al. (2002). They reported that HADS had "*excellent case finding abilities*", with an area under the ROC curve (AUC - the tests discriminatory power between case and non-cases) of between 0.84 and 0.96. The concurrent validity of the HADS when compared to other scales of a similar nature was also described by Bjelland et al. (2002). It was shown to have similar sensitivity and specificity to the General Health Questionnaire (GHQ). Further still, the correlation of the HADS-anxiety and HADS-depression subscales when compared to other similar questionnaires in use (such as the Beck Depression Inventory) the correlation was between 0.6 and 0.8, which Bjelland and colleagues described as medium (good) to strong (very good) correlations.

6.5.8.2 Perceived social support

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al. 1988) (Appendix 19) was chosen as it has been used in previous research involving carers of people with dementia (Charlesworth et al. 2008; Marziali & Garcia, 2011). This tool has been validated for use in older adults and has a high level of reliability and validity (Stanley et al. 1998).

The MSPSS aims to measure the level of perceived social support participants are currently experiencing from 12 items which are scored on a Likert scale ranging from one to seven (Table 15). There are three subscales to this questionnaire which measure perceived support from three sources: significant others (SO) (Items 1, 2, 5, and 10), family (FA) (Items 3, 4, 8, and 11) and friends (FR) (Items 6, 7, 9, and 12). The total possible score ranges from 12 to 84 and from four to 28 on each of the subscales. The MSPSS has been described as:

> "*self-explanatory, simple to use and time conserving – features that make it an ideal research instrument for use when subject time is limited and/or a number of other measures are being administered at the same time*" (Zimet et al. 1988, p. 33).

These were further positive aspects to the MSPSS which helped the decision to choose this scale for measuring perceived social support.

Table 15. Scoring for MSPSS

Scoring for each item
1 = Very strongly disagree
2 = Strongly disagree
3 = Mildly disagree
4 = Neutral
5 = Mildly agree
6 = Strongly agree
7 = Very strongly agree

Reliability. The internal consistency of the MSPSS was reported by Zimet et al. (1988) in a study of University students under the age of 22. Cronbach's alpha was documented as 0.88 for the whole scale. For the significant other, family and friends subscales the reliability was found to be 0.91, 0.87 and 0.85. The test-retest reliability was reported as 0.85 for the whole scale and 0.72 for significant other, 0.85 for family and 0.75 for the friends subscales after a two or three month interval. Further, the scale has been shown to have strong internal test-retest reliability when used in older adults with or without psychiatric illness (Stanley et al. 1998). Test-retest reliability was found to be 0.73 for the scale as a whole, 0.74 for family, 0.73 for friends and 0.53 for significant other subscales.

Validity. The validity of the MSPSS was described by Zimet et al. (1988). It was shown how the scale has strong factorial validity (the 'family', 'friends' and 'similar other' subscales correlate with social support) a moderate level of construct validity.

6.5.8.3 Loneliness

The University of California-Los Angeles (UCLA) Loneliness Scale (version 3), (Russell, 1996) (Appendix 20), was chosen to investigate reported loneliness. This scale has been previously used to investigate loneliness in carers of people with dementia (Beeson, 2003) and Parkinson's disease (McRae et al. 2009). Version three of this scale has also been validated for use in elderly populations (Russell, 1996). The sample reported in the Russell (1996) study consisted of university student, nurses, teachers and elderly populations, with the elderly population reporting the lowest levels of loneliness (M = 31.51) and the Nurses (40.14) and students the highest (40.08).

This self-report questionnaire has 20 items which are scored on a Likert scale ranging from one (never), two (rarely), three (sometimes) and four (often). The minimum possible score is 20 and the maximum 80, with higher scores indicating greater feelings of loneliness. To reduce the prospect of response bias with earlier versions of the scale, this revised version of the UCLA loneliness scale included 11 negatively worded (lonely) and 9 positively worded (not lonely) items (Russell, 1996). This has led to questions 1, 5, 6, 9, 10, 15, 16, 19 and 20 being reverse scored (for example, a participant reporting 'never' on question 1, was marked as four on the Likert scale).

Reliability. The UCLA Loneliness Scale (version 3) has been shown to be very reliable, with internal consistency ranging from 0.92 for students, to 0.89 for elderly populations (Russell, 1996). In the elderly population test-retest reliability was strong, with a 0.72 correlation being found after a 12 month gap between first and second administration.

Validity. There is evidence to suggest that the UCLA Loneliness Scale (version 3) has strong convergent validity, with correlations between it and other measures of loneliness, for example, the Social Provisions Scale (Russell, 1996).

6.6 Qualitative phase methods

Carers were asked to take part in a single interview. Volunteer mentors were providing either befriending or peer support, although they did not need to be new to the service.

6.6.1 Eligibility criteria

Carers were eligible to take part in this phase upon completion of the three month follow up questionnaires. Volunteers could take part if they were delivering befriending or peer support to carers of people with dementia for more than six months prior to interview. It was expected that this would have given them adequate experience in order to answer the questions fully.

6.6.2 Sample size

Initially it was planned that carers were to be sampled based upon their score in the quantitative phase. However, due to a small sample size and reluctance of some carers to take part in this qualitative phase, all carers were contacted with half agreeing to participate. In total ten volunteer mentors were recruited to take part in the qualitative phase.

6.6.3 Recruitment procedure

6.6.3.1 Carers

As reported elsewhere (Greenwood et al. 2013) in order to gain maximum diversity among carers, all 16 who had not withdrawn from the research were contacted inviting them for interview to share their experiences of volunteer mentoring over the previous three to six months. The carers were contacted by telephone to determine whether they wished to take part in the one off interview about their views and experiences of volunteer mentoring. If they agreed, a day and time was arranged to either visit them at home or conduct a telephone interview.

6.6.3.2 Volunteers

Volunteer mentors were non-probability purposefully sampled to take part in this phase, which involved asking the service managers to assist in identifying volunteers who fitted the inclusion criteria (section 6.7.1). Volunteers were initially sent an information letter (Appendix 16) and SAEs which gave them space to indicate whether they wished to take part. If a response was received, they were contacted to arrange an appropriate time to either visit them at home or conduct a telephone interview.

6.6.4 Data collection

Qualitative data were collected from carers and volunteers using semi-structured interviews. These were carried out between July 2013 and March 2014. Interviews took place at the participants' home or over the telephone at a time convenient for them. The researcher introduced himself and again explained the research before asking if they would still like to take part. The approach is exploratory in nature and semi-structured interviews allow for rich and in-depth data collection (Morse & Field, 1996) of an area about which little is known (systematic review findings, Chapter Four). A reflective diary was kept of all interviews. This was used to highlight the transparency of the data collection process and to understand how the researcher could have introduced potential bias (documented in the limitations, Chapter Eight).

Reflexivity is important when conducting qualitative research as it not only contributes to the confirmability of the qualitative findings. but can show "*...how the researcher might have directly impacted on the research process and conclusions*" (Watkins & Gioia, 2015, p. 89-90). Interviews lasted from between 20 and 45 minutes and 17 of the 18 (both carers and volunteers) were audio recorded. Detailed notes were taken during one interview as one volunteer mentor orally withdrew consent to it being audio recorded. Of the eight carers who agreed to being interviewed, six were conducted face-to-face and two over the telephone. All six face-to-face interviews took place at the carers' home. Seven volunteer mentors' interviews were conducted over the telephone. The remaining three interviews were face-to-face at the volunteers' home.

6.6.1 Topic guides

Topic guides were used in order to make sure important a priori areas were covered (e.g. matching and experiential similarity), (Bowling, 2002). Topic guides for carers and volunteers were similar in design, this allowed for the 'mixing' or triangulation of findings from both carers and volunteers. The only difference between the forms for carers were the replacing 'befriending' with 'peer support' depending on the intervention received. The same can be said for the volunteers' questionnaire. The topic guide for carers (Appendix 21) consisted of questions relating to the experiences and potential impact on them, the volunteers and the potential impact on them, experiential similarity and matching. Carers were also given the opportunity to discuss other issues at the end they wished to talk about. Similarly, the topic guide for volunteers (Appendix 22) focused on their experiences of volunteer mentoring, the potential impact it has had on them, experiential similarity, matching and how they perceive volunteer mentoring impacts on carers.

6.6.2 Data analysis

Qualitative data gathered from interviews with carers and volunteers were transcribed and analysed for themes (Auerbach & Silverstein, 2003) using Framework Analysis (Richie & Spencer, 1994). The qualitative data analysis software package NVivo 10 (QSR International, 2012) was used to assist in organising the data. Analysis of the qualitative data began during the data collection phase.

The frameworks were developed after 'data familiarisation', then revised further after 'data indexing' and final frameworks were developed after 'data charting'. The frameworks for carers are available in Appendix 23 and the frameworks for volunteers in Appendix 24. Initially, all transcripts were read in order to enable familiarisation with the data and make general notes about the main ideas from each in the margins using the track changes function in a Word document. Secondly, a second researcher (NG) read four transcripts and made notes in the margins. From this the initial framework was developed which was applied back to the transcripts to check how well it fitted the raw data. This led to a further refinement of the framework in which themes and subthemes were merged together and agreement was reached by both analysts regarding the emerging themes and subthemes. The final stage was 'charting', in which the data were summarised in an Excel file. These summaries included short notes about themes and subthemes and the location of the associated data (using page numbers) in the transcripts. This stage enabled an overview of the data as a whole and led to a further refinement of the final framework. These steps provide an audit trail for the data analysis and show the direct links between the final framework and the transcripts.

6.6.3 Framework analysis

Framework analysis has become an established and rigorous method for analysing qualitative data in health services research (Furber, 2010). It has also been used to analyse data from in-depth interviews from different groups of participants (Richie & Spencer, 1994). Framework analysis was developed in the 1980's by the National Centre for Social Research (NCSR) and involves a number of distinct but interconnected stages (Dixon-Woods, 2011; Richie & Spencer, 1994). Richie and Spencer (1994) suggest a systematic five step process to conducting framework analysis, this can be conducted concurrently with the qualitative data collection or when data collection has been completed:

1. *Familiarisation.* This stage involves the researcher becoming immersed in the data and gaining an overview of the richness, depth and diversity of the data. This can be through the listening of the audio tapes, and the transcribing and rereading of the transcripts. During this stage key ideas and recurrent themes are listed for future examination.

2. *Identifying a thematic framework.* During this stage a framework is developed based on key issues and themes from the familiarisation stage and from *a priori* issues (such as the research questions). This framework can then be revised and developed during later stages.

3. *Indexing.* This is the process of applying the thematic framework systematically to all of the data in its textual form. Numerical or textual codes are used to identify data which corresponds to different themes. As suggested by Richie and Spencer (1994), a numerical system for indexing will be used.

4. *Charting.* In this stage the data which were indexed can now be arranged into themes using headings from the thematic framework. This helps to build up a picture of the data as a whole. Charts were constructed for each theme across all participants.

5. *Mapping and Interpretation.* This final stage involves the analysis and pulling together of key characteristics of the data. Richie and Spencer (1994, p. 186) describe this as the most difficult of the five phases, and when the researcher attempts "*defining concepts, mapping range and nature of phenomenon, creating typologies, finding associations, providing explanations and developing strategies.*" Richie and Spencer highlight that which of these a researcher may attempt is guided by the original research questions and by the themes which emerge from the data.

Framework analysis is useful in that "*it provides a clear track of how data moved from interview to transcripts to themes*" improving dependability (Ward et al. 2013).

6.6.4 Dependability

Dependability, as described by Guba and Lincoln (1989), is capturing the changes to the research design and changing conditions due to the nature of reality being socially constructed. This involved the researcher providing descriptions of changes during the data collection process highlighting that the results are subject to instability (Creswell, 2013).

6.6.5 Intercoder agreement

Analysis of the transcripts was conducted by two researchers (RS and NG). Intercoder agreement is often used in qualitative health science research (Creswell, 2013) where researchers want an external check on the coding process. Two researchers met initially to discuss the coding process, followed by meeting after the coding of four transcripts to check on levels of agreement with codes and themes (Creswell, 2013).

6.6.6 Validity

There are a number of different validation strategies for qualitative research, with Creswell (2013), recommending at least two procedures are used in any given study. Three procedures were chosen and are documented below.

6.6.7 Clarification of researcher bias

Merriam (1998) highlights that one way to ensure validity in qualitative research is by:

> "*...clarifying the researcher's assumptions, worldview, and theoretical orientation at the outset of the study*".

This is further highlighted by Creswell (2013, p. 251), who states that:

> "*...the researcher comments on past experiences, biases, prejudices, and orientations that have likely shaped the interpretation and approach to the study*".

The world views were stated in the methodology chapter and how they have influenced the approach to this research. However, there are a number of other potential areas of bias which need highlighting. The researcher had worked with both carers and volunteers in the voluntary sector for nearly two years prior to starting this PhD. He has seen the potential benefits and negatives of volunteer led peer support, subsequently the topic guides were followed when interviewing participants to try and avoid unconsciously influencing participant responses. The researcher had also conducted a systematic review and survey of service managers as part of this research which could have potentially impacted on what he expected to find.

6.6.8 Rich, thick descriptions

The second validation procedure used is to provide rich, thick descriptions about the participants (Creswell, 2013). This allowed for transferability, as readers will be able to identify if the findings can be transferred to other studies (Lincoln & Guba, 1985).

6.6.9 Triangulation

Triangulation was used to assess the conformability of the data to assure accuracy of the findings (Patton, 2002). The triangulation of data allowed for confirmation of results by comparing data across all participants. This also adds credibility to the research. The use of triangulation is discussed in greater detail in this chapter in section 6.8 with regards to data integration.

6.6.10 Member checking

Despite some researchers arguing for its use (Shenton, 2004), member checking was not conducted. This is due to the possibility of causing confusion and not confirmation due to participants potentially not remembering what they have said (Morse, 1994). There is also the possibility participants may not be able to recognise their experiences in the synthesised data and want their accounts removing (Morse et al. 2002).

6.6.11 The researcher within the study

This section is written in a first person narrative. I have used a mixed methods approach, with pragmatism as the umbrella framework. Post-postivism was used for the quantitative phase and constructivism for the qualitative phase.

I undertook a Master's degree in Psychiatric Research which was heavily focused on quantitative research methods. My undergraduate degree in Psychology was also centred on quantitative methods, with little exploration of qualitative method and even less about using mixed methods approaches to research. However, despite this I feel it is necessary to use a pragmatic approach by using the methods which work best to understand the impact of volunteer mentoring, this is based on my previous experience working in the voluntary sector with carers and people with dementia.

My range of work experiences prior to starting this PhD largely included being in a role helping others, from being a Support Worker helping those with enduring mental illness, to being a Dementia Advisor working in the voluntary sector helping people with dementia and their carers. The desire to encourage and empower people to help themselves was part of both roles. During my time as a Dementia Advisor, I made daily visits to people with dementia and their carers in the community to give advice, information and practical help, such as assistance with form filling. I was interested to know what impact my work was having on the carers' lives from a practical point of view, as well as a more personal understanding of the experiences of each.

The Dementia Advisor service was evaluated quantitatively, without exploring the experiences of the carers accessing the service. Whilst I understood the importance of quantitative data collection to 'prove the services worth' to commissioners, I felt that carers should have been given a chance to express the positives and negatives of their experiences in accessing the service, subsequently the quantitative findings were less informative without the views and contributions of the carers to the evaluation. I was also working alongside volunteers who were dedicating their lives to helping carers and I wanted to understand the impact of their support on carers and to understand the volunteers' experiences and perceptions of delivering a peer support intervention. It was during this time this PhD research investigating volunteer mentoring was advertised at Kingston University. Through investigating this, I hoped to be able to improve the experiences of carers and volunteers.

At the time of being a Dementia Advisors I was 25 and would often receive comments from both carers and professionals surrounding whether or not I have adequate experience to offer advice to people (often elderly) who have spent many years caring. Also, as a male in what was a female dominated role, carers sometimes expected help from a female. This led me to wonder whether the carers, particularly female carers, I was helping would feel comfortable talking about their difficulties or were expressing fully the help they needed from me. I will return to these issues and explore them further in the discussion (Chapter Eight) of this research in relation to reflective diaries I have kept.

6.7 Mixing data

This research used methodological triangulation (Denzin, 1970). As already stated, this main PhD research has a sequential explanatory design (Creswell & Plano Clark, 2011), with the priority given to the quantitative methods. O'Cathain et al. (2010) suggests three methods for integrating data for mixed methods studies, the triangulation protocol, following a thread and the mixed methods matrix. Given that the present research collected both qualitative and quantitative data from the same carers, this method was used to highlight discrepancies between the quantiative outcomes and the in-depth interviews. The integration of quantitative and qualitative data for carers and qualitative findings from carers and volunteers, was conducted during the overall interpretation in the findings chapter (Chapter Seven).

6.8 Ethics

The conduct of the research was informed by Economic and Social Research Council Framework for Research Ethics (ESRC, 2010). Ethical approval was gained from the Faculty Research Ethics Committee (FREC) on 03/02/2013. The research protocol and ethics application for Phase Two are available in Appendix 25. Key ethical considerations are described below.

Informed consent was obtained from all participants before data collection. The consent form for carers taking part in the quantitative phase is available in Appendix 26. The consent form for carers and volunteers taking part in the qualitative phase is available in Appendix 27. Before any data collection began, the purpose of the research, confirmation that their participation is voluntary and the participants' right to withdraw at any time were repeated verbally. They were informed that they were under no obligation to answer any of the questions and did not have to give a reason for not doing so.

All participants were informed that their responses to the questionnaires were confidential and that they would be kept in a locked cabinet on University premises. An identification number was used to enable the identification of questionnaires from the same individuals. Identifying information (such as names, addresses and other personal information) present in qualitative interviews was anonymised during transcribing. Participants were informed that no personal details that could identify them would appear in future publications and that no information they provided would be made available to volunteer mentoring services. The names, telephone numbers, addresses and identification numbers were stored in a separate file on a password protected University computer.

Participants were informed that should information be shared indicating a vulnerable adult is being harmed, this information would be shared with relevant authorities (such as social services) according to local safeguarding vulnerable adults procedures.

Participants were informed prior to starting the interview that they could withdraw at any time without giving a reason and the information they have provided would be destroyed if they wished.

6.9 Conclusion

In conclusion, this chapter introduced the researchers' philosophical assumptions and reasons for adopting a pragmatic approach to mixed methods research. It also documented a comprehensive background to mixed methods research, pragmatism and its place in the current research. The pragmatic paradigm highlighted the importance of the research questions, making it the most appropriate choice for the current research. The mixed methods approach has pragmatism as its base, and draws on constructivist and post-positivist epistemologies. The methods of phase Two have been described in full. Next, the findings are presented in Chapter Seven, followed by the integration of evidence in Chapter Eight.

7 Chapter Seven: Findings

7.1 Introduction

This chapter reports the quantitative and qualitative findings from Phase Two. First, the results from the longitudinal quantitative survey of carers are presented. Second, the findings from the qualitative semi-structured interviews with carers and volunteer mentors are described. Integration of the quantitative and qualitative findings for carers and qualitative findings from both carers and volunteers are documented in the final sections of the chapter.

7.2 Results from the longitudinal quantitative survey of carers

The results are presented in the following order: Demographic details, participation over time, primary outcome and secondary outcomes.

7.2.1 Carer participation and demographic details

Nineteen carers were enrolled at baseline. Retention was 100% at three months follow-up and 84% at six months follow-up (three carers withdrew from the study - Figure 5). The low response rate (14%) was similar to that of Charlesworth et al. (2008) of 15% when recruiting carers of people with dementia through voluntary sector organisations.

The age of carers who took part in the quantitative phase ranged from 34 to 85 (average 63.6) and were largely female (14 - 73.7%). The majority of carers were spouses of the person with dementia (13 - 68.4%) and nearly half had been caring for less than three years (9 - 47.4%). Full demographic details of the carers are available in Table 16. Carers were often receiving a number of other support interventions at study enrolment. These ranged from visits from an Admiral Nurse, support from social services and attending support groups. However, six carers indicated they were receiving no support apart from the befriending or peer support service (Table 17). The majority of carers were caring for someone living at home (17 - 89.5%) and with a diagnosis of Alzheimer's disease (10 - 52.6%) (Table 18).

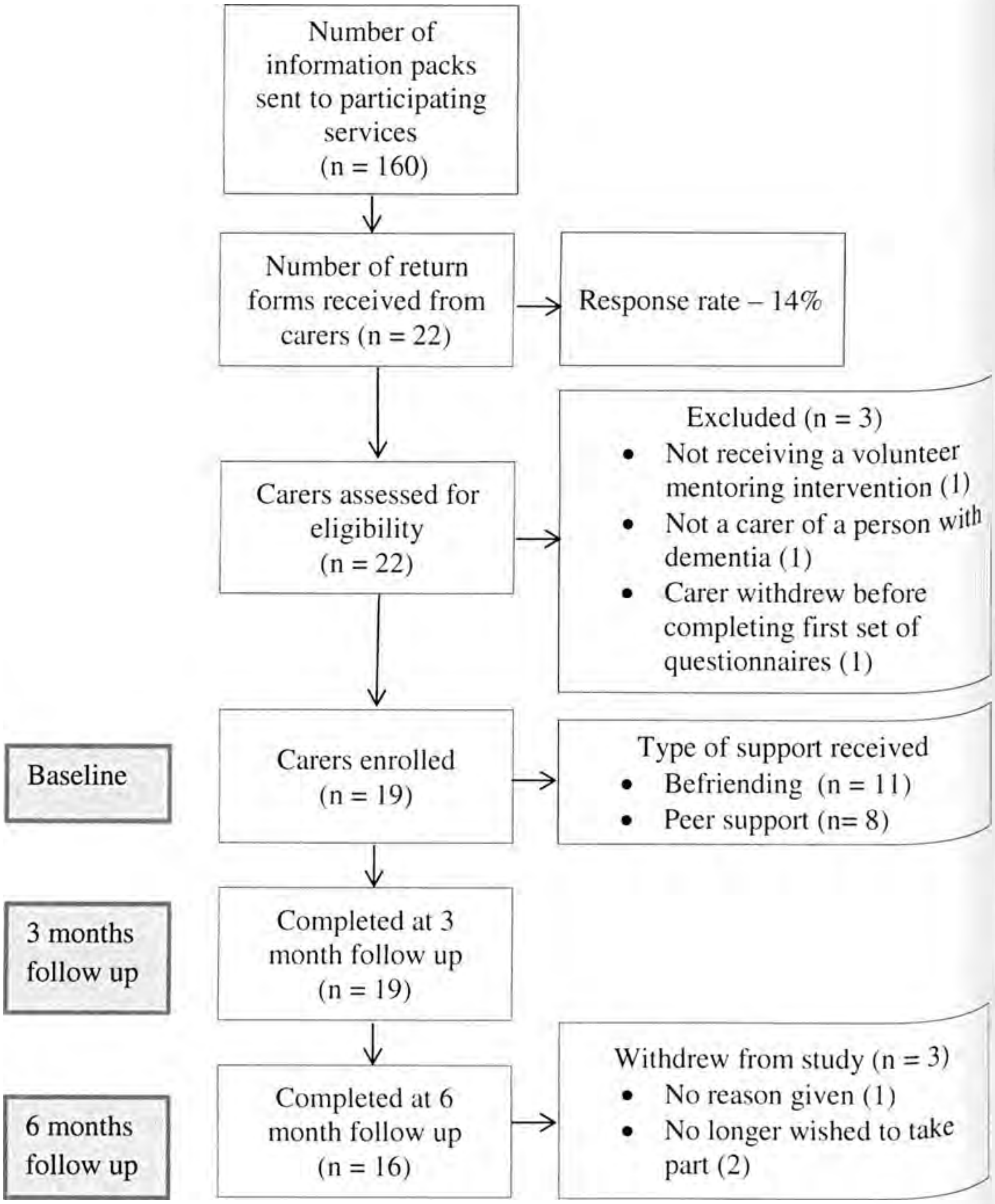


Figure 5. Flow of carers from baseline through to final data collection.

Table 16. Carer participant demographic details

		Carers (n = 19)
Mean age in years (range)		63.6 (34-85)
Gender		
	Female	14 (73.7%)
	Male	5 (26.3%)
Marital status		
	Married	16 (84.2%)
	Single	3 (15.8%)
Ethnicity		
	White	18 (94.7%)
	Missing	1 (5.3%)
Nationality		
	British	14 (73.7%)
	English	1 (5.3%)
	Missing	4 (21.1%)
Relationship to PWD		
	Spouse	13 (68.4%)
	Adult child	5 (26.3%)
	Adult grandchild	1 (5.3%)
Length of time caring		
	< 3 years	9 (47.4%)
	3 – 5 years	7 (36.8%)
	6 – 8 years	3 (15.8%)

Table 17. Support interventions received by carers at study enrolment

		No. of carers (%)
Intervention type		
	Support group(s)	9 (47.3%)
	Admiral Nurse	6 (31.5%)
	Care manager (social services)	3 (15.7%)
	Respite	2 (10.5%)
	Assistance with form filling/benefit entitlements	2 (10.5%)
	Family/friends	2 (10.5%)
	Healthcare visitor	1 (5.2%)
	Dementia cafe	1 (5.2%)
	Sing-a-longs	1 (5.2%)
	None	6 (31.5%)

Table 18. Dementia type and residential status of the people with dementia

		People with dementia n = 19 (%)
Dementia type		
	Alzheimer's disease	10 (52.6%)
	Mixed dementia (Alzheimer's and vascular)	3 (15.8%
	Vascular	2 (10.5%)
	Familial Alzheimer's disease (FAD)	1 (5.3%)
	Fronto-temporal dementia	1 (5.3%)
	Dementia with Lewy bodies	1 (5.3%)
	Unknown	1 (5.3%)
Residential status		
	Own home	17 (89.5%)
	Residential care	2 (10.5%)

7.2.2 Primary outcome: change in levels of depression

The primary outcome measure was change in HADS depression scores (HADS-D) between baseline and six months follow up, and the study had been powered on a change in HADS-D score of two at six months follow up. The number of carers with reported depression dropped by one at three months (from four to three), but rose again to four at six months (Table 19).

Table 19. Carers with and without HADS reported depression

		Baseline (n = 19)	**3 months (n = 19)**	**6 months (n = 16)**
HADS *depression*				
	Depressed	4	3	4
	Not depressed	15	16	12

*Carers were considered depressed with scores of 11 or more

There was a trend for HADS depression scores to reduce over the three time points (Table 20 and Figure 6) but this was not statistically significant (χ^2 (2) = 0.448, p = 0.79). These results suggest that being in receipt of volunteer mentoring has no overall significant positive impact on the levels of depression of carers over the course of six months.

Table 20. HADS, UCLA and MSPSS scores at baseline, three months and six months follow up

***n = 16**		**Baseline**	**3 months**	**6 months**	***p* value**
HADS ***anxiety***					
	Mean (SD)	8.94 (4.15)	8.69 (4.78)	8.63 (4.31)	$p = 0.78$
	Range	4-16	2-17	3-15	
HADS ***depression***					
	Mean (SD)	7.13 (4.04)	6.81 (4.21)	6.94 (4.41)	$p = 0.79$
	Range	2-13	1-16	1-15	
UCLA					
	Mean (SD)	49.13 (7.16)	46.56 (9.98)	46.13 (9.01)	$p = 0.19$
	Range	37-61	30-64	30-61	
MSPSS (overall)					
	Mean (SD)	52.69 (11.70)	61.06 (10.27)	58.38 (8.40)	$p = 0.042$
	Range	34-80	40-79	42-71	
MSPSS ***(family)***					
	Mean (SD)	16.44 (7.06)	18.13 (5.72)	17.5 (5.65)	$p = 0.58$
	Range	4-28	4-25	4-25	
MSPSS ***(friends)***					
	Mean (SD)	17.50 (4.67)	20 (4.85)	20.38 (4.67)	$p = 0.20$
	Range	11-28	11-28	12-28	
MSPSS ***(Significant others)***					
	Mean (SD)	19 (4.81)	22.94 (4.43)	21.19 (4.82)	$p = 0.004$
	Range	8-28	12-28	13-28	

*Three participants did not complete the six months follow up and were excluded from the analysis

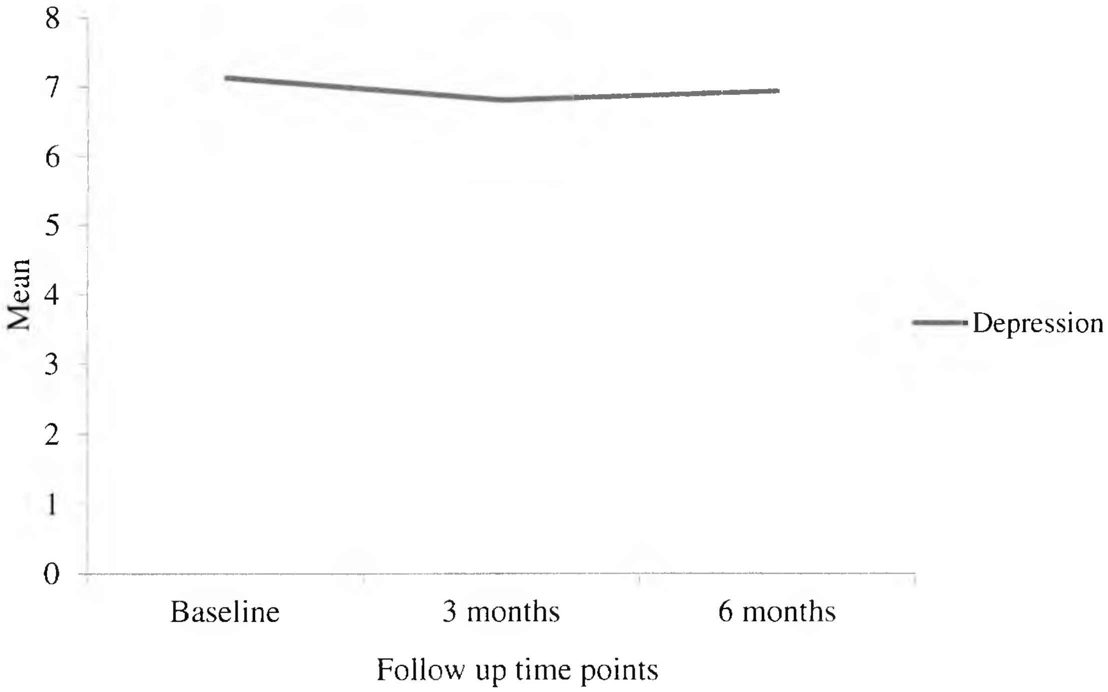


Figure 6. Mean HADS depression scores over time

7.2.3 Secondary outcomes

7.2.3.1 Anxiety

There was a trend for reductions in anxiety scores between baseline, three months and six months (Table 20 & Figure 7), but this was not statistically significant ($\chi^2(2) = 0.491$, $p = 0.78$). The number of carers with reported anxiety remained at six across the three times points. Carers were more likely to report being anxious rather than depressed (Table 21).

Table 21. Carers with and without HADS reported anxiety

		Baseline (n = 19)	**3 months (n = 19)**	**6 months (n = 16)**
HADS *anxiety*				
	Anxious	6	6	6
	Not anxious	13	13	10

*Carers were considered anxious with scores of 11 or more.

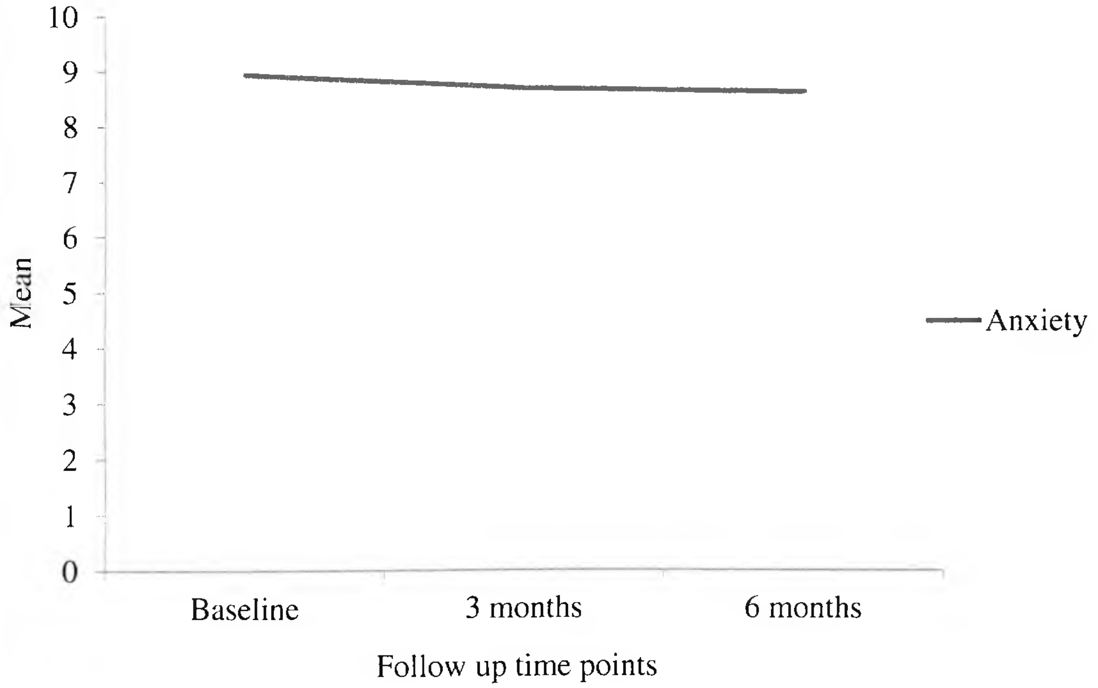


Figure 7. Mean HADS anxiety scores over time

7.2.3.2 Loneliness

There was a trend for reductions in mean reported loneliness scores between baseline (49.13, SD = 7.16), three months (46.56, SD = 9.98) and six months (46.13, SD = 9.01), but this was not statistically significant (χ^2 (2) = 3.226, p = 0.19), (Table 20 & Figure 8). These results suggest volunteer mentoring is not an effective intervention for reducing loneliness in carers of people with dementia.

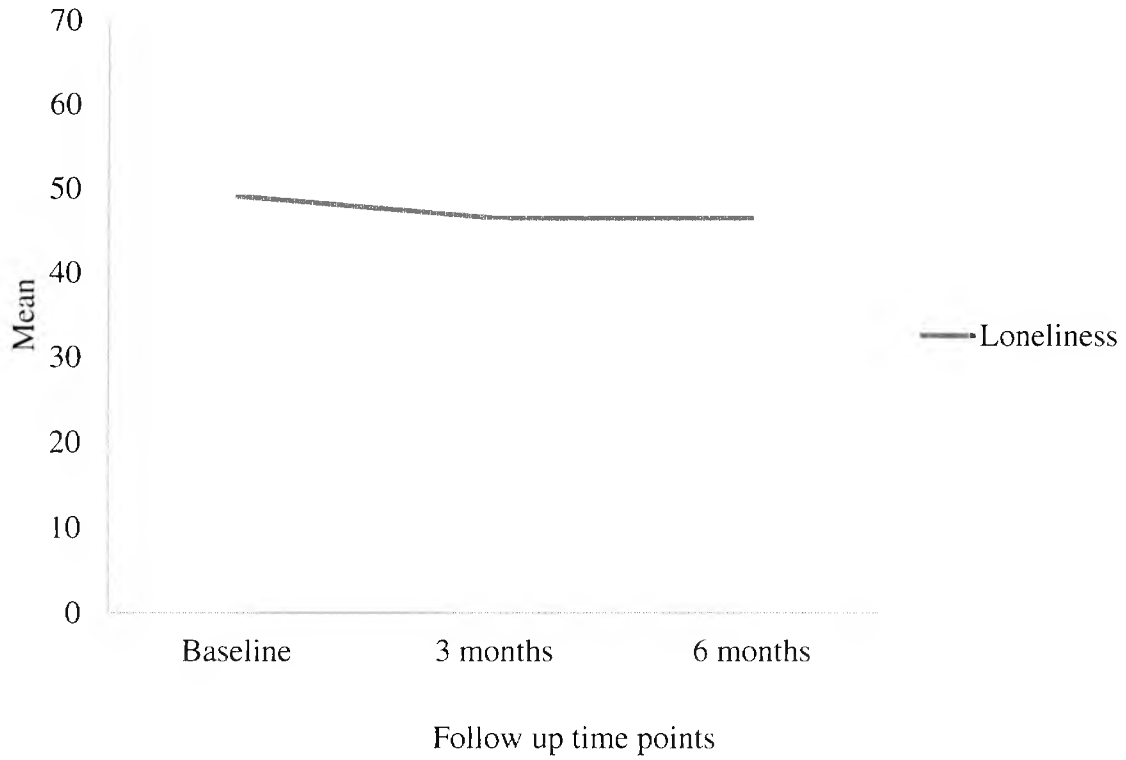


Figure 8. Mean UCLA loneliness score over time

7.2.3.3 Perceived social support

There was a statistically significant difference in overall perceived social support between baseline, three months and six months follow up (χ^2 (2) = 6.317, p = 0.042), (Table 20 & Figure 9). Post hoc analysis were carried out with Wilcoxon signed-rank tests with a Bonferroni correction, with a new significance level being set at 0.017 (α = 0.05/3 = 0.017). Median (interquartile range) perceived social support scores for baseline, three months and six months were 53 (44 to 60), 60 (55 to 67) and 60.5 (49.25 to 64.75) respectively. Despite an increase in overall perceived social support, there were no statistically significant differences between baseline and six months (Z = 1.683, p = 0.092) or between three months and six months (Z = -1.061, p = 0.289). However, there was a weak but statistically significant increase in overall perceived social support between baseline and three months (Z = 2.442, p = 0.015).

Mann-Whitney U tests were carried out in order to identify if any statistically significant differences in overall perceived social support between baseline and three months among the independent variables gender and intervention type. No statistically significant differences were found between gender at baseline (U = 28.00, Z = -0.64, p = 0.51) or at three months follow up (U = 33.00, Z = -0.18, p = 0.85). Similarly, no statistically significant differences were found between intervention type at baseline (U = 38.50, Z = -0.45, p = 0.65) and three months follow up (U = 33.00, Z = -0.90, p = 0.36). These results indicate that gender and intervention type had no bearing on overall perceived social support scores.

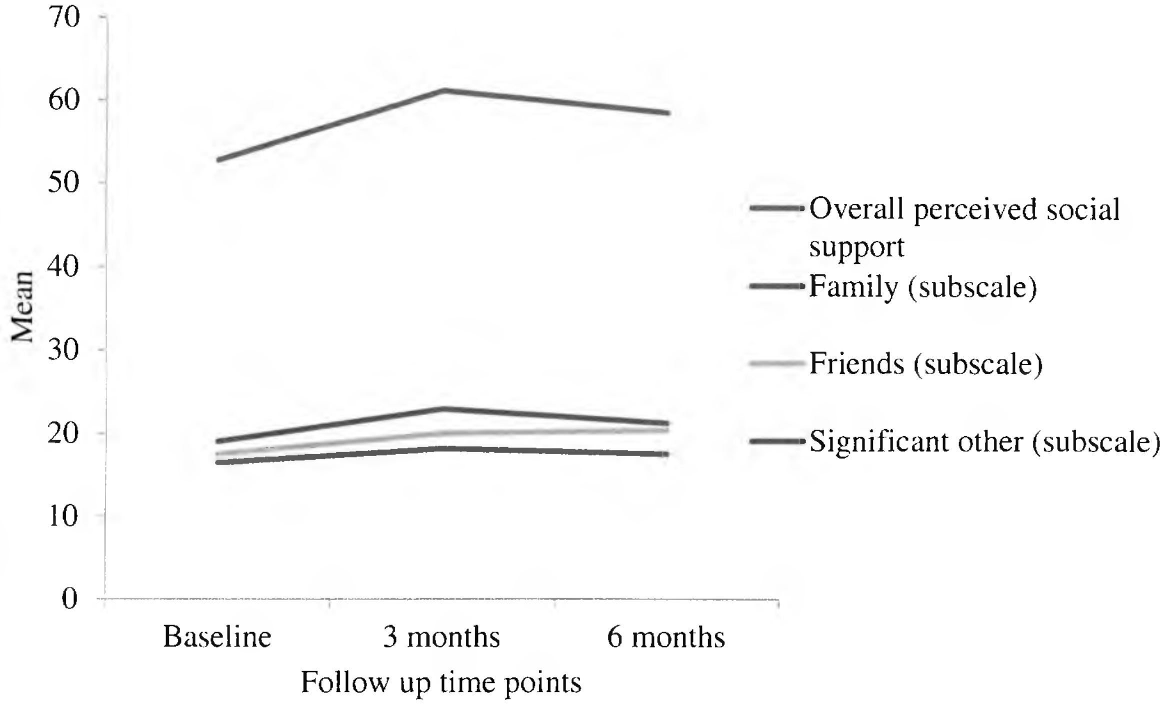


Figure 9. Mean MSPSS scores over time

7.2.3.4 *MSPSS subscales*

The three subscales of the MSPSS (family, friends and significant others) were subjected to the Friedman test as was the MSPSS overall scores. There was a statistically significant difference in perceived social support from significant others between baseline, three months and six months follow up (χ^2 (2) = 11.179, p = 0.004), (Table 20). Post hoc analyses were carried out with Wilcoxon signed-rank tests with a Bonferroni correction, with a new significance level being set at 0.017 (α = 0.05/3 = 0.017). No statistically significant difference was found between baseline and six months follow up (Z = 1.582, p = 0.114) or between three months and six months follow up (Z = 1.937, p = 0.053). However, there was a statistically significant increase in perceived social support from significant others between baseline and three months follow up (Z = 2.487, p = 0.013).

Mann-Whitney U tests were carried out in order to identify if the statistically significant difference in perceived social support (significant others) between baseline and three months extended to the independent variables gender and intervention type. No statistically significant differences were found between gender at baseline (U = 30.50, *Z* = -0.41, *p* = 0.68) or at three months follow up (U = 27.50, *Z* = -0.69, *p* = 0.50). Similarly, no statistically significant differences were found between intervention type at baseline (U = 36.50, Z = -0.62, p = 0.54) and three months follow up (U = 26.00, *Z* = -0.13, *p* = 0.15). These results indicate that gender and intervention type had no bearing on perceived social support scores for the significant others subscale.

7.3 Findings from semi-structured interviews with carers

7.3.1 Carer demographic details

A total of eight carers took part in the qualitative phase (five were receiving peer support and three befriending) and their demographic details are available in Table 22. Interviews lasted between 17 and 52 minutes and took place face-to-face at the carers' home (6) or over the telephone (2). The mean age of carers was 64.1 years, five were female (62.5%) and all described their ethnicity as White. To protect their anonymity, carers and volunteers have been assigned pseudonyms.

Data analysis was conducted using Framework Analysis (Furber, 2010) and is documented in Chapter Six (section 6.7.15). The final framework is available in Table 21.

7.3.1 Themes

The themes were divided into two sections. First, the views of carers regarding the aspects of volunteer mentoring they valued. This has two subthemes: experiential similarity and volunteer characteristics. Second, carers' perceptions of their experiences of the support are reported. This has three themes: carers feel listened to, someone there just for the carer and the reciprocity of support. Themes and subthemes are described in Table 23.

Table 22. Carer participant demographic details (qualitative phase)

		Carers (n = 8)
Mean age in years (range)		64.1 (41-85)
Gender		
	Male	3 (37.5%)
	Female	5 (62.5%)
Marital status		
	Married	7 (87.5%)
	Single	1 (12.5%)
Ethnicity		
	White	8 (100%)
	Missing	0
Nationality		
	British	6 (75%)
	English	1 (12.5%)
	Missing	1 (12.5%)
Relationship to PWD		
	Spouse	6 (75%)
	Adult child	2 (25%)
	Adult grandchild	0
Length of time caring at study enrolment		
	< 3 years	3 (37.5%)
	3 – 5 years	4 (50%)
	6 – 8 years	1 (12.5%)

Table 23. Final framework developed after data charting (carers)

Themes	**Subthemes**
Aspects of volunteer mentoring carers value and enable the development of successful relationships	• Experiential similarity • Volunteer characteristics
Carers feel listened to	• Safe environment • Sustaining emotions • Getting through difficult situations
Someone there just for the carer	• Advice and information • Personalised support • Carers look forward to the support (enjoyment) • Reduced social isolation
Reciprocity of support between carer and volunteer	• Sharing between carer and volunteer • Volunteer well-being • Volunteer enjoyment

7.3.2 Aspects of volunteer mentoring that carers value and enable the development of successful relationships

Within this overarching theme there were two sub themes: experiential similarity and volunteer characteristics.

7.3.2.1 Experiential similarity

The experiential similarity of volunteers, in terms of former personal caring experience of a person with dementia, was one of the most important elements of volunteer mentoring reported by carers. Although this was something they valued about the volunteers, it was also linked to a number of other themes and subthemes. For example, because of their own experiences, some volunteers were able to pass on advice and information about practical issues such as benefit entitlements and other available support services. Advice based on personal experiences such as different ways in which to approach difficult situations was also seen as important, helping carers feel more confident in coping when difficulties arise. Also, the sharing and reciprocity of support was often facilitated by the volunteers' prior caring experience, as it enabled the carers and volunteers to build stronger and trusting bonds. This was crucial to the formation of a safe environment in which to share feelings, as one carer explained it was the prior caring experience which made it possible:

> Sue. "*I think because to understand what somebody's going through I think that person needs to experience...have had experience of something of that situation...and it gives them the ability to understand better how you're feeling and how to help you...because I don't think anyone understands better than someone who has been in the same situation, you know, on how to cope or give advice or even help*".

It was commonly reported by carers, that if the volunteer understood the situation through the shared experience of caring, it helped carers to express their emotions and talk about the difficulties they faced. One carer commented how it would be frustrating if the volunteer lacked prior caring experience:

> Laura. "*If someone has no idea about dementia or I think most have Alzheimer's then you know, I mean that could be a bit frustrating...I need to talk about all these things with someone who gets 'it'.*"

Other carers emphasised again that prior caring experience of volunteers enabled them to relay information and ideas on how to deal with difficult situations. For example, one carer reported the value for him was knowing the volunteers' advice was from her own experiences:

> Charles. "*Well I just think it helps with her being able to pass on knowledge really...or to say things like "I did that" or "have you tried this?", I know she didn't read it in a book she's actually been there herself, for me it's really important.*"

7.3.2.2 Volunteer characteristics

Other carers talked about how having a volunteer of a similar age and having similar interests helped them to bond faster. Generally female carers reported having a female volunteer was important, with the carer below specifically asking for a female befriender and another who assumed she would be matched with a female. When asked if they knew if they were matched with volunteers prior to support starting, she responded:

> Emma. "*Umm, well on gender yes, but that was because I asked for a female....not sure if that counts?*"

Some of the male carers did not suggest the gender of the volunteer would be an issue, however having a similar personality and interests were important to them. When asked about the possibility of matching, a male carer replied:

> David. "*...I like the idea of having somebody who's a similar age and a few similar interests so we can gel together a bit better so I always would think that's a good idea, yeah....I like the idea of that.*"

Some carers felt if the volunteers were unable to listen properly or talked about themselves too much, then they would benefit less from the support. Listening carefully was an important skill mentioned by the majority of carers and links to helping the carers express their emotions and offload their concerns. One carer suggested that if the volunteers do not listen carefully, it is unlikely to be possible for them to successfully offer help or advice. Carers would also not feel as though the volunteer was taking an active interest in their situation:

> Wendy. "*That's right, to be able to listen....to listen before you make a comment, you've got to be able to understand the person's problems before you pass some sort of judgment on them, you know. So yes listening is very important, not to just rattle off.*"

Other volunteer characteristics viewed as important to carers were a cheerful and positive attitude, being sympathetic and empathetic, and a warm person who is patient and considerate. These were all thought to expedite the formation of a bond between carers and volunteers and enabled the carers to feel comfortable in showing emotions and sharing difficulties.

Carers' experiences of volunteer mentoring

This section is divided into three main themes (carers feel listened to, someone there just for the carer and reciprocity of support) with associated subthemes.

7.3.3 Carers feel listened to

Carers described the importance of being listened to by the volunteers. However, this went deeper than simply being listened to in a literal sense. Three subthemes were identified: creating a safe environment, the sustaining of emotions and getting through difficult situations. A safe environment gave space for carers to share personal information which lead to a sustaining of their emotions through the offloading of thoughts and feelings. This in turn helped them to get through difficult situations encountered with caring.

Subthemes:

7.3.3.1 Creating a safe environment

Carers indicated the importance of a safe environment, which involved feeling comfortable with and trusting the volunteer with personal information. There were a number of factors which contributed to this feeling of 'safety', for example a volunteer who is non-judgemental and unbiased:

> Wendy. "*Umm...well I thought...just to have somebody to talk to...who's non-judgemental and I thought it would be good to have someone to share my experiences with...that will always be helpful.*"

Highlighting that no one model of support works for all carers, some discussed how they felt it was easier to share personal information or discuss 'taboo' issues, such as personal care, on a one-to-one basis as opposed to in a group setting:

> Laura. "*...not forgetting that some things are a bit taboo to talk about you know. I can bring it up with *volunteer name* but not so much with the group...I mean some would find it uncomfortable...some of the older ones there perhaps...they wouldn't want to listen to any of that.*"

Another aspect which carers reported enabled them to feel comfortable and less inhibited in talking about difficult topics was the experiential similarity of volunteers. This links back to trusting the volunteer when discussing certain topics and, as later discussed, the importance of experiential similarity. This facilitates the development of an environment where carers can offload emotions and talk about difficulties openly with the carer feeling safe knowing the volunteer understands their point of view and can offer a listening ear without judgement:

> Sue: "*...I think having somebody who knows the situation you're in...I think she knows how to talk to me better because of it and I don't feel inhibited talking to her about problems I have. You know, she knows my situation because she was in the same boat. She understands what is happening so if there's a situation where most people would 'oh God that's awful' she say something like 'it's all right I've been there and done it', you know, so I think it's like...we share the same feelings and have the same involvement because she cared for her husband at one point. She knows exactly what I'm going through and I don't feel I have to be somebody I'm not.*"

7.3.3.2 Sustaining emotions

Whilst most carers did not discuss improvements in any depression or anxiety, they did talk about how befriending and peer support could give them an emotional boost or lift. However, a number of carers stressed that this emotional boost was dependant on the continued support of the volunteer, with some carers drawing attention to the temporary nature of emotional benefits:

> Charles. "*...I mean it's nice she's here and all that, but my problems are still here when she leaves again. Perhaps whilst she's here I feel better, but that's it...I feel OK within myself anyway, what with all the support I get elsewhere.*"

For some carers the feeling that they were now being cared for was linked to their sense of emotional support:

> Sue. "*Because you look after the person who has the dementia but who cares for you? You know I think that's an important question in a lot of these cases...you know, you know nobody looks after you as the carer so that does help.*"

Another carer also highlighted that a reason for the emotional lift was being able to put things in perspective:

> Laura. "*When someone's listening you always feel better then...once you've spoken to someone it puts things into perspective then, a different way of looking at it.*"

An aspect to volunteer mentoring which was linked to the sustaining of emotions was the ability to express thoughts and feelings. Carers referred to this as 'letting off steam', being able to 'sound off' or use the volunteer as a 'bouncing board'. Carers also talked about how they found it difficult to express these thoughts and feelings to a family member or close friends and the volunteer gave them the opportunity to do this:

> David. "*A problem shared is a problem halved and all that. Not to use too many old clichés....but yes I think so, I mean umm and sometimes it nice not to offload all your problems to family or people you've known for a long time....you feel that it's too much.*"

Being able to offload thoughts and feelings and the improvements in emotional sustainability may improve carers' coping ability and enable them to keep on caring for longer:

> Sue. "*...it's* (peer support) *been an absolute rock for me and if it hadn't of been for *volunteer name* I don't think I would have been able to cope as well as I have, and umm I think there's not enough of it to go around and not enough people to deal with it.*"

Whilst the majority of carers were unsure if receiving volunteer mentoring resulted in improvements for the person with dementia, three carers did suggest ways in which they thought it had helped. In particular, their improvements in emotional health and the ability to offload thoughts and feelings with the volunteers helped them to maintain a more harmonious relationship with the person they are caring for:

> David. "*...obviously my umm, there is a benefit from the point of me being in a better frame of mind. So I think as long as I'm happy she'll be happy.*"

Similarly, two carers talked about how their mood can affect the person being cared for and how volunteer mentoring has helped them not to lose their temper so quickly and be more patient:

> Wendy. "*Of course, of course, I mean sometimes I get uptight and I'm sure it rubs off on the people you're caring for and it's not good to lose your temper when you know it's not through their fault that they're forgetful. I mean sometime I've come back and I've been much happier than before I left, so...yeah perhaps it's helped our relationship too, I don't know.*"

The sustaining of emotional health and reported improvements in relationships with the person with dementia helped carers feel more in control of difficult situations as they arose.

7.3.3.3 *Getting through difficult situations*

Carers talked about how volunteer mentoring helped them to get through some difficult situations. This was a result of being able to talk things through with the volunteers in order to learn how to cope with challenging behaviours and being able to see that other carers have experienced similar issues. This enabled some carers to feel more confident in their own caring abilities and to cope better with difficulties:

> Henry. "*It sets you up to cope with it a bit better, I think. You don't really want to fight a battle alone, you'd rather win the war with a bit of help...that's what I wanted*".

Other carers talked about how the support more generally enabled them to carry on and get through adversity. For example, one carer talked about how it helped her to get through some difficult times and had helped her to continue in her caring role:

> Sue. "*Well it's held me up...it's been there when I needed it and it's been very helpful to give me the courage to carry on...it's very difficult*".

7.3.4 Someone there just for the carer

A theme which emerged was how the carers felt that there was someone there for them as opposed to the person with dementia. Initially carers talked about the practical benefits of receiving volunteer mentoring, such as advice about benefit entitlements and information about other support services. However, carers also discussed the importance of flexibility and personalisation of support, for example, frequency of support and topics discussed. These first two subthemes were linked to carers looking forward to the support. The final subtheme concerns reductions in social isolation, and was associated with having someone (the volunteer) there to help with their needs and to give them something to look forward to, as one carer put it:

> Sue. "*...Yeah...I mean you're there to help the person that you're caring for but you need help as well...it took me a long time to understand that but I do now, and it is very important that there is somebody there for you...and *volunteer name* is there for me...*"

Subthemes

7.3.4.1 Advice and information

Carers valued the varied advice and information that the volunteers can provide, viewing them as an important resource. They talked about the provision of information regarding specialist local transport organisations, care agencies and other relevant services they or the person with dementia may need to access. Most notably, the importance of volunteers being able to pass on information about potential financial entitlements was highlighted. Carers talked about becoming aware of the benefits they could be entitled to, volunteers helping them to obtain the relevant forms and assistance with form filling:

> Wendy. "*She* (the volunteer) *also mentioned something recently about the benefits I can get…the carers allowance and I'm looking into that now…because I'm a fulltime carer and I wasn't even aware that I could claim for that.*"

This was a useful aspect to volunteer mentoring, especially for those carers who lacked confidence with applying for financial support and for those who had difficulty with form filling:

> Emma."*…now I have her on my side…it's a nice feeling, yeah.*"

The type of advice and information given varied and carers valued the understanding from volunteers that each situation is different, and that they were able to offer a tailored and personalised approach to support.

7.3.4.2 Personalised support

Part of 'being there for the carer' involved support tailored to their individual needs. Carers talked about the importance of flexibility in terms of the frequency of support, with some being comfortable with seeing the volunteer every two weeks as opposed to weekly. Carers and volunteers also often decided between themselves the best way to communicate, with some using telephone and email contact, as well as face-to-face meetings:

> Wendy. "*Sometimes email…I mean I know I can call her if I want. I have her number…but email is good so we can arrange where to meet up and if there's any other things I want to talk about. You know if I do want to meet up with her weekly then she finds the time for me…but generally it's very flexible*"

Carers described the importance of being able to talk about things more generally outside the caring situation and to 'have a laugh', as well as talk about more personal and emotive topics. Other carers used the time with the volunteer to go out or to play games:

> David. "*Umm, well it's quite a loose format....we generally talk for about an hour and we talk about what we've been doing over a cup of coffee....umm sometimes we play a game of something, sometimes scrabble or chess. As I said it's quite a loose format...*"

This flexibility over support type and not just talking about difficulties with caring helped the carers feel the support was something to look forward to, and often, enjoy.

7.3.4.3 Carers look forward to the support

Carers talked frequently about how they looked forward to seeing the volunteer due to feeling isolated. Some carers talked about how they rarely had the chance for social interaction due to their caring role or their own ill health, and that seeing the volunteer gave them something to look forward to. For example, one carer who felt socially isolated because she was unable to leave her house often due to health issues looked forward to the company:

> Mary. "*Oh yes, well I don't get many visitors and as I say I can't get out much...not at my age...not with my leg. So it's nice to see *volunteer name* and I can talk to someone who's been through all this.*"

For others, anticipation related to the thought of seeing someone who was likely to cheer them up:

> David. "*Yes it gives you a lift then and then after a few days I might have gone back to a...lower level of...umm...it's like a...less happy mood, but then I look forward to seeing him again.*"

7.3.4.4 Reduced social isolation

The reduction of social isolation was a common topic discussed by carers. There were a number of reasons why carers felt isolated. These included reduced mobility due to their own ill health, most of their time being spent on their caring role and family and friends being at a distance. Carers talked about feeling less alone with their problems since receiving volunteer mentoring and that they now had someone to turn to, as one carer described:

> Henry. "*...umm I feel part of something, if I've got a problem...rather than just a loner...I suddenly felt as if someone's gathered me in.*"

Some carers talked about how, over time, they developed friendships with the volunteers and how this further reduced their feelings of isolation:

> David. "*Well obviously I can only speak from my own individual case, but umm I think we are more friends really, it's not a task where it's a job or a burden for him, I think he enjoys it…*"

One carer stressed that although she saw health professionals, she did not have contact with someone she can be relaxed around and talk about difficult subjects with. This made volunteer mentoring especially important to her as she struggled to leave the house due to ill health and her caring responsibilities:

> Mary. "*Well…I see so many medical people…nurses, doctors, you name 'em. But she's just normal, you know? Like me…you know…I don't have to pretend with her that things are OK when they're not.*"

Whilst the majority of the time carers reported positive aspects of receiving volunteer mentoring, a male carer highlighted little or no improvements on loneliness or emotional well-being. When asked if it has improved any loneliness he may have been feeling, he responded that whilst he no longer felt alone with his problems, it had not impacted on loneliness:

> Henry. "*…not particularly I don't think. I tend to think things through as far as I can, but sometimes one or two facts come out, particularly when I've talked to my family about it and that sort of thing *coughing* sorry I've got a groggy throat. But umm apart from that I think it's just to know you're not really alone on these things although you can't always find a lot of understanding from people in general I feel.*"

7.3.5 Reciprocity of support

Carers often talked about ways in which they thought volunteers also benefitted from volunteer mentoring. This theme has three connected subthemes, the sharing of information and feeling between carers and volunteers, the volunteers' well-being and finally the enjoyment volunteers get from their role.

7.3.5.1 Sharing between carer and volunteer

The sharing which takes place between carers and volunteers was not only seen as central to the development of volunteer mentoring relationships, but carers also thought it enabled volunteers to benefit by offloading painful memories and feelings. For example, one carer suggested that although she knew the volunteer was there to help her, she acknowledged that there is a mutual benefit:

> Wendy. "*Well I feel, as I've said, it's a two way street, we both get something from it…but I mean she's tasked with providing something so I'm getting more out of it than her…*"

Other carers described how this sharing and the depth of the topics discussed were often dependant on how the volunteer was feeling on the day:

> David. "*…but umm it depends on* (volunteer name) *as well, what sort of week he's having. We sort of feed off each other and see how we feel and then we can maybe go by that and umm yeah that's it*"…"*…as I said if he's having a bad day then we'll not talk about anything too serious but umm yeah if we're both in a reasonable mood then we can perhaps delve into a few of the problems and have…yeah it's nice to just see how things go really*"

Whilst carers talked about improvements in their emotional health and social isolation, they also highlighted that the sharing of personal difficulties gave volunteers an opportunity to talk about their own current difficulties and potentially resulted in their improved well-being.

7.3.5.2 Volunteer well-being

When carers were asked in what ways, if any, they thought volunteers benefit from their role, the reduction of loneliness and increased social inclusion were discussed. According to the carers, volunteering gave volunteers an opportunity to do something constructive as well as fill their time. Carers also suggested there are psychological and physical benefits of volunteering. In particular carers mentioned how it helps to get the volunteer 'out of the house' and this, they thought, could be associated with maintaining physical health by keeping active. Other carers talked about how they feel volunteering helps keep volunteers in a positive frame of mind, or that the carer may try and help boost the volunteers' mood if they perceive them to be feeling low:

> Wendy. "*I'm aware she befriends other people as well so I can understand it could be a bit depressing for her…so I try sometimes not to tell her too much about the downside and keep it upbeat…*"

One carer suggested that there is a link between mood improvements for volunteers and reducing loneliness through volunteering:

> Charles. "*But doing anything where you're getting out and meeting new people is going to help in my view*"

The ability to share their own past and present difficulties and the potential improvements in their own physical and emotional well-being, are some of the benefits carers thought enabled volunteers to enjoy their supportive role.

7.3.5.3 Volunteer enjoyment

The final subtheme linked to the perceived reciprocity of support is volunteer enjoyment and the reasons why volunteers may enjoy volunteering. Carers talked about how the enjoyment volunteers get could be linked to 'giving something back' to the services they have previously used and the satisfaction in knowing they are successfully helping others:

> Henry. "*...she's doing good for someone else, so I'm sure it makes her feel good*"

> Wendy. "*...well...umm she said one time when I was down and me seeing her...she could tell I was lifted and she said that made her feel happy...umm it lifts her up as well*"

Carers also thought that volunteers' enjoyment was linked to them having a renewed sense of purpose. For example, one carer suggested how volunteering had given one peer supporter a role and feeling valued after she retired:

> Mary. "*She had quite a high flying career in the city I believe...now she's a big deal where she is now....sorry if that came across badly...I'm trying to say she's filling in for what she used to do...*"

However, whilst carers largely reported the beneficial nature of volunteer mentoring on the volunteers' health and well-being, this was not always the case. Two carers highlighted it could bring back painful memories for the volunteers about their own past caring experiences, and whilst one carer suggested this could be therapeutic for volunteers, being able to deal with their own feelings and those of the carers could prove challenging:

> Sue. "*...I should think it's quite hard for her sometimes you know, I know she's been through the same situation as me, but err I would think possibly it would even bring back the memory...the memories of her situation of when she had to look after her family members...*"

Another carer explained that she would be unable to carry out the volunteer's role due to the possibility of reliving her own difficult experiences:

> Emma. "*Not to mention that it would bring back all the memories of my husband....when he passes over I don't want reminding of all these things...*"

7.3.1 Deviant cases

The following is an exploration of the findings from two carers who took part in both phases of the data collection. These carers were chosen for having the greatest changes in scale scores over the six months study period.

7.3.1.1 Increased anxiety

Emma was receiving a befriending service and had been caring for her husband who has vascular dementia for four months at study enrolment. Her anxiety increased from normal (7) at baseline, to mild (10) at three months and to moderate (11) at six months. However, her level of depression was unchanged (normal) and she had reductions in loneliness from baseline (37) to six months (30) and an increase in perceived social support (62 at baseline to 70 at six months). She reported that she was not receiving any other form of support. When interviewed, she mentioned that she has not noticed any changes within herself in any way, however befriending was useful as it gave her someone to share her difficulties with and be networked into other services:

> Emma: "*...it's nice to know what's out there for me and* (person with dementia name) *and she is a great resource, but I'm not entirely sure I would say that's a change within myself in anyway*"

This carer highlights the lack of impact on mental health befriending has on some carers over time and that, in this case, a large reported increase in anxiety was evident. With dementia being a progressive condition, this could indicate how carers can become increasingly stressed over time and that a befriending intervention on its own may not be enough to help support carers.

7.3.1.2 Decreased perceived social support

Charles, a 71 year old male receiving peer support, had been caring for his wife who has Alzheimer's disease for six years. He had no significant changes in depression, anxiety or loneliness over the six months study period. However, he had a large drop in perceived social support over that time (80 at baseline, 61 at three months and 58 at six months). He was receiving a number of other support interventions at study enrolment, including visits from an

Admiral Nurse, two days respite per week (wife attends a day centre) and he also visits his local Dementia Café approximately once per month. When interviewed he described how he viewed assistance from the peer supporter in a very formal way in that she was there to help him. When asked about the possibility of a friendship developing he responded:

> Charles: "*I wouldn't go that far. I mean I wouldn't meet up with her outside of the time we meet here….*"

One explanation for this is that he could have become increasingly isolated over the study period due to an increase in his caring responsibilities. However, it could also be symptomatic of males viewing peer support as a way of gaining information to assist them with caring and not as a way of gaining emotional support and forming bonds with others.

7.4 Findings from semi-structured interviews with volunteer mentors

7.4.1 Volunteer mentor demographic details

Ten volunteers agreed to be interviewed about their experiences of volunteer mentoring (seven befrienders and three peer supporters). Volunteers' age ranged from 29-80 years (average 58.8) and the majority were female (7). Nine of the ten were White British and one Black African. There was an even split of volunteers who were or were not former carers. Full demographic details of the volunteers are available in Table 24. The final framework was developed in the same way as with the data from carers and is available in Table 25.

7.4.1 Themes

Three main themes were developed from the data (Table 25). The first theme, developing a bond, has three subthemes: experiential similarity, volunteer characteristics and common interests. The second theme, someone for carers to talk to, has four subthemes: carers feel listened to, emotional support, social inclusion and coping ability. The final theme, helping themselves through helping others, also has four subthemes: mutual benefits, making a difference, burden on volunteers and part of a bigger picture.

Table 24. Volunteer mentor demographic details

		Volunteers (n = 10)
Mean age in years (range)		58.8 (29-80)
Gender		
	Male	3 (30%)
	Female	7 (70%)
Marital status		
	Married	2 (20%)
	Single	3 (30%)
	Widow	3 (30%)
	Divorced	2 (20%)
Ethnicity		
	White	9 (90%)
	Black African	1 (10%)
Nationality		
	British	9 (90%)
	Nigerian	1 (10%)
Former carer		
	Yes	5 (50%)
	No	5 (50%)
	Currently caring	0
Length of time volunteering		
	< 1 year	4 (40%)
	1-3 years	4 (40%)
	4+ years	2 (20%)

Table 25. Final framework developed after data charting (volunteers)

Themes	**Subthemes**
Developing a bond	• Experiential similarity • Volunteer characteristics • Common interests
Someone for carers to talk to	• Carers feel listened to • Emotional support • Social inclusion • Coping ability
Helping themselves through helping others	• Mutual benefits • Making a difference • Burden on volunteers • Part of a bigger picture

7.4.2 Developing a bond

Developing a successful volunteer mentoring relationship was reported to be dependent on the strength of bonds formed between carers and volunteers. The most important elements volunteers described were experiential similarity, followed by the characteristics they felt were important for volunteers to have, and finally that there needed to be common interests between carers and volunteers to enable the development of longer lasting and mutually beneficial relationships.

7.4.2.1 Experiential similarity

Of the ten volunteers, half had experience of caring for a relative who had dementia. Those volunteers who had experiential similarity described it as important in forming a connection with this carer describing:

> Chloe: "*...well, understanding, to understand what people are going through. And that's because you've been through it yourself and then you can understand how...I think that's the main thing really is being able to understand what they're going through and umm, sometimes it helps them to know you've been through the same thing...*"

Those volunteers without prior caring experience were able to see how it could be beneficial for the carer by being able to share with someone who has gone through similar experiences, and to provide advice and information:

> Elizabeth: "*Actually, I've never thought that maybe you'd be even better if you'd had that personal experience yourself. Yes, maybe that person, it would be even better for them if the befriender was somebody who'd actually been through it themselves. I'd never thought about it, but yes, that might well be true*"

Further highlighting the importance of experiential similarity, one volunteer described how carers may become frustrated if she did not have prior caring experience:

> Ruby: "*...yes like I said I think the carers would find it difficult if I didn't have that. They get lots of information from me because of it*"

Experiential similarity was seen as an instant common bond, which volunteers suggested helped to build trust and enable the development of longer lasting volunteer mentoring relationships:

> Jack: "*We had the same problems of looking after people who need help and rely on you a lot, who you have to spend 24 hours a day sometimes with. We had that bond really.... It's just trust, you trust somebody. We have the same bond*"

Passing on information and advice due to having personal experience of being a carer was reported to be an important part to befriending and peer support to those volunteers with prior caring experience, as a way of passing on knowledge of how to deal with challenging situations and to offer advice about other services available:

> Abby: "*Having been a carer I felt I was much more...able to have empathy for them or maybe some kind of sympathy. When they (the carer) says what they (the person with dementia) are doing I can understand and really mean it, and then offer advice because I know how hard it is...*"

As well as giving advice on how to deal with challenging behaviours, volunteers described how they would often give practical advice on benefit entitlements and form filling:

> Abby: "*I asked one lady is she getting the top rate for her attendance allowance and she said "No, I'm not", and I said "Well, you ought to be because you're up and down all night". So she applied and I helped with that and it was successful. I had to do all that myself and I didn't have anybody to help me do any of it...*"

As a result of offering advice due to her prior caring experience, one volunteer talked about how it boosted the carer's self-confidence:

> Abby: "*It's also advice, it probably comes over to them as advice. I just tell them you need to be a bit more forceful asking for what you want and tell them what happened when I did...it helps them with their confidence and being more assertive*"

7.4.2.2 Volunteer characteristics

Whilst experiential similarity was considered a major factor in developing bonds with carers, there were other important characteristics volunteers felt it important they have. For successful and supportive relationships to develop, volunteers mentioned a number of different characteristics they felt were needed, including patience, empathy, a sympathetic nature, reliable and a warm and caring personality. However, the importance of listening skills was highlighted as key in successfully helping carers. For example, in order to assist carers effectively and allow them the opportunity to offload and share their emotions:

> Mark: "*...being able to listen carefully to what they are saying, it's no use just me talking about my life all the time, it's a time for him to share and get all his stuff off his chest he might be bottling up*"

Another aspect volunteers talked about as important was having a cheerful personality and a good sense of humour. Volunteers felt this had an impact in two ways, firstly to assist in developing a bond with carers:

> Ngozi: "*...being very humorous, being able to make them laugh...they tend to enjoy your company if you're a funny person...it's nice to laugh once in a while*"

Secondly, volunteers felt that having a sense of humour and being able to laugh with carers helped to give them a lift and to boost their mood:

> Alice: "*...if you can have a laugh and a joke I think that goes a long way to helping someone, to help their mood*"

Volunteers having these characteristics helped the initial development of the volunteer mentoring relationships, however having common interests was seen by volunteers to enable the connection to carers develop further.

7.4.2.3 Common interests

Whilst volunteers felt that there were a number of basic characteristics it was important for them to have, they suggested that being able to develop deeper and longer lasting volunteer mentoring relationships with carers depended on there being common interests. This was also important for the sharing of personal information to take place. However, one volunteer stated sometimes it is not possible to connect with carers and the relationship fails to develop:

> Abby: "*...but then again there are some people you will never make a connection with aren't there? There was this one lady she was very difficult and* (manager name) *said "if you can't get through to her then no one will" and then she* (the carer) *just said I made her feel worse*"

Volunteers reported that they were also matched to carers by service managers based on who they thought would get along with, on proximity to the carer, personal interests and hobbies. Volunteers suggested matching was important for developing bonds, but also for their own enjoyment:

> Elizabeth: "*Oh, definitely. It made me want to get quite enthusiastic about talking to her as well*" and "*…she's very much into the arts so we found common ground almost immediately.*"

Some volunteers described how it was important for them to be matched with carers based on gender and age, as they felt it was more likely they would have things in common with the carers and enable them to develop a stronger bond:

> Chloe: "*…most of the people I see are either a couple of years younger than me or a couple of years older than me…so there's a same generation and I think that's important. There's no good you speaking to an 80 year old if you are 20…or 25…you've not got a great deal in common have you?*"

However, some volunteers felt being matched on age was not so important as gender and that it was important that matching takes place in order to help the initial development of the volunteer and carer relationship:

> Harry: "*…females generally get matched with females. I think also that age is not so important as is maturity, but yes I would say there is a matching that goes on at some level, yes*" and "*…let's say I was asked to help an older lady, who was uncomfortable with a lone male being in her house, well that wouldn't really work, would it?*"

7.4.3 Someone for carers to talk to

Volunteers discussed how giving carers the opportunity to talk and to share emotions or challenges that they might not be able to share with anyone else, was an important part of the support they offer. Volunteers also expressed how this led carers to feel less isolated or lonely and enabled them to cope better with some aspects of caring they might be finding difficult. Volunteers suggested that this could have an indirect positive impact on the person with dementia through achieving a more harmonious relationship with the carer.

7.4.3.1 Carers feel listened to

Volunteers described how the carers they support often had few other people to talk to regarding the challenges and difficulties with caring. In particular, volunteers suggested that carers find it difficult talking to family and friends, this was often due to not wanting to burden or worry them with their problems. Volunteer mentoring offered them a chance to have their feelings heard:

> Abby: "*To give them somebody to talk to…they may not have told anybody what they've told me. Because you do tend to keep it away from your family, you don't want to worry people.*"

Sometimes volunteers suggested that some family member may not understand the difficulties they are experiencing:

> Alice: "*The chap I'm befriending I talked about just now, his family don't understand…it's not like they don't have the time…I guess it's hard to talk about it within families for some people. So he can talk to me about things that he can't otherwise.*"

As well as family, volunteers suggested that carers also find it difficult sharing their difficulties and concerns with friends:

> Elizabeth: "*She's got friends but I don't think, if people came to visit, that she would want to burden them with talking about whatever she needs to.*"

Being able to talk openly and to confide in volunteers about difficult topics was something volunteers said carers did frequently and this was a way of helping them to feel better:

> Elizabeth: "*Quite a few things had happened where her husband at one point started getting a bit violent and that was a bit scary for her. Then one time she'd fallen down stairs. I found that after talking to her for about 10 minutes she would really perk up.*"

7.4.3.2 Emotional support

Volunteers suggested that the provision of emotional support to carers was something they did on a regular basis and that they can give carers 'a shoulder to cry on' by just being there and listening. Volunteers also understood that this was an important part of their role and that it was beneficial for carers to release or offload their emotional stress:

> Chloe: "*…you know, it's like if you're having a bad day it sometimes helps to tell somebody, especially somebody that you're not close to*"

However, one volunteer suggested the emotional benefits do not last and that regular support for carers is needed due to the difficulties of caring for a person with dementia:

> Elizabeth: "*If I put myself in her position, it would cheer me up for the day, probably, but it's such a huge thing, isn't it, having to look after somebody, a partner, who's got dementia?*"

When asked if a volunteer had seen any positive changes over time with the carer he had been supporting, Harry suggested that there were no emotional benefits for the carer outside of the time they spent together due to dementia being a progressive condition:

> Harry: "*Erm, no not really. And I think that's due to the nature of his wife's illness. It's only going one way and he's confronted with that every day. I mean I can't lay any claim to improving his well-being unfortunately, apart from those few hours a week*"

7.4.3.3 Social inclusion

Volunteers described how the carers they supported were often socially isolated or lonely. They suggested there were a number of different reasons for this, ranging from losing touch with family and friends, to not being able to leave the house often due to their caring responsibilities. Volunteers suggested there were a number of positives for carers as a result of being more socially included. Reduced loneliness, improved emotional well-being and increased physical activity were the most common potential benefits described. As a result, volunteers talked about how helping carers to feel less alone with their difficulties was a priority:

> Jack: "*Well I think maybe some are a bit lonely, they just want someone to share their experiences with...obviously everyone has got their own circumstances and no two people are the same but yes, I think loneliness, just to share their experiences and just someone to talk to*".

Some volunteers indicated that they made friends with the carers and that this was another way of helping carers to feel less socially isolated.

> Alice: "*It's chance for them to make new friends, they don't get chance to get out or speak to people*".

A number of the volunteers reported that for some carers who were caring for a person with advanced dementia, it was a chance to talk about current affairs or more general things other than their caring role:

> Chloe: "*Yeah, because you see they could be...they could get up in the morning and their husband or wife doesn't say anything, you can't sit and...you know if you listen to the news, you get up and put the television on and watch the news in the morning, you can't discuss it with them...you know and it's nice to socialise, even if it's a discussion about world affairs...*".

One volunteer described from her own personal caring experience how she became cut-off socially and this was the reason she decided to become a befriender:

> Abby: "*…because you don't have any time off it's a 24 hour job. Yes is was 24 hours…I still tried to have a bit of a life without him because that's very important…to get out, but it's not always possible, especially as things progress you find yourself even more alone and cut off*".

7.4.3.4 Coping ability

Volunteers talked about how carers were more likely to be able to cope better with difficult situations as a result of receiving befriending or peer support. In particular, it helped carers to feel they were not alone with their problems and that other people have experienced similar challenges and successfully got through them:

> Chloe: "*You know they think well we're not the only ones that behave like this, I think that helps*".

Some volunteers suggested that the person with dementia benefited indirectly from the carer receiving support. This was described in different ways, but overall they viewed it as helping the carer to keep going which resulted in the person with dementia staying at home longer before moving into residential care:

> Ngozi: "*Yes it really does because the carer doesn't feel isolated anymore so as I said they can keep going. All this I think helps them to cope…I guess so the person with dementia can stay longer (at home) before needing to go to residential care*".

They considered that the carer became more relaxed as a result of the support and then they were more likely to be patient with the person with dementia:

> Mark: "*…at the time though he seems more relaxed. I think all this helps the person with dementia too. I mean (carer name) is much more relaxed these days and that's better for her (person with dementia). He's more likely to be patient if he's more relaxed right? So it's surely having a knock on effect for her…in a positive way*".

Another volunteer suggested that carers were likely to get less irritated with the person with dementia if they were able to have a break away from caring to talk to someone else and take part in activities they enjoy:

> Jack: "*I think it gets a bit stale. No matter how much you love them, you can get a bit irritated but you need a break and spend some time doing something else, then you can*

perform better I think in your activities. If you spend too long doing the same thing it gets a bit tiresome really".

7.4.4 Helping themselves through helping others

Volunteers explained how whilst they were there to provide support to the carers, volunteering had also enriched their lives through the reciprocal nature of the support. Along with this, they also discussed feeling as though they were making a positive difference to someone's life which was rewarding and important for them to continue with volunteering. Despite this, volunteers reported a number of issues which they felt placed a burden on them and that supervision and training could be ways to help alleviate this. Finally, the volunteers explored how volunteer mentoring was just one way in which carers find support and that no one service would be adequate for all carers or their issues.

7.4.4.1 Mutual benefits

Volunteers explained how carers look forward to, appreciated and enjoyed spending time with them as it was a chance for them to share experiences and have social contact. This was due to a number of reasons, including being able to share in common interests, reducing loneliness and for some carers a chance to get away from their caring responsibilities for a short time:

> Ngozi: "*...she's happier I think and is always looking forward to my visits. She says she's looking forward to my next visit before I've even left...she likes to get out...she doesn't get many visitors*".

Volunteers talked about how carers appreciate the flexibility over the frequency, duration and type of support. For example, some volunteers communicated over telephone or email and some carers were able to express to volunteers how best they would like to be supported. Some volunteers talked about how some carers prefer not to talk about their caring role and they do things they both enjoy and rarely stick to the one hour a week they were initially asked to volunteer for:

> Emily: "*I took her to a concert. When I've had more time, I've taken her to things. We've been to galleries together and things, or whatever we decide we feel like doing. Those events often will take longer than an hour*".

Whilst volunteers described a range of benefits they feel carers get from the support, they also explained how it can positively impact upon their lives. Most notably they described how it can improve their mood by being able to share their past and present difficulties with the carer, highlighting the two way nature of support:

> Jack: "*He would explain his memories and his sad moments and likewise I'd do the same. We can feel a sympathy, we both empathise with each other obviously, we both share those experiences. It's obviously nice to have…*"

One volunteer talked about how she became depressed after retiring and that becoming a befriender not only helped her recover, but also boosted her self-esteem and feelings of self-worth:

> Elizabeth: "*…befriending is just one of the things that's given me a bit more self-esteem…You give up that 9 till 5 every day bit of your life and you've suddenly got all this time…it has so enriched my life. I actually, after retiring, went through a period of feeling very low. I went to see my GP who then said it might help if I became a volunteer and told me about the Volunteer Centre. So it went on from there*".

Further highlighting the two-way nature of support, some volunteers talked about how they developed friendships with the carers and that this has had a positive impact on their lives through reducing their own social isolation and loneliness. A volunteer described how being able to be a peer supporter helped her to become more socially integrated after years of caring for her husband:

> Ruby: "*Well after my husband died…well that was a number of years ago now, I felt like I had no life of my own anymore. Everything I did revolved around him, obviously it was a dreadful time, but in the end I needed to get back out there and find a life of my own again. This really helped me…it helped a lot to get me back on my feet*".

Many of the volunteers talked about enjoying the company of the carers, but male volunteers more often talked about spending time away from the home of the carer, engaging in activities they both enjoy and help them both to relax, such as sports or going to a restaurant:

> Harry: "*He likes to have a couple of pints…his way of de-stressing I would think, so there's a variety of pubs we like that do food and nice beer. And that's what we both like I guess… So we go out and we talk mostly about everyday things that interest us both, like football, family, what we both used to do before we retired*".

As well as emotional and social benefits, some volunteers found that befriending (as opposed to peer support) offered them the chance to gain experience, whether that was to enhance their job prospects after leaving university or as a way of gaining the experience necessary for them to retain. Whilst this highlights a potential benefit for volunteers, it was noted that service managers are becoming wary of allowing students to volunteer due to reliability issues:

> Mark: "*I think it's down to reliability...not turning up sometimes when they say they will. But also they finish their course and you don't see them for dust...she* (service manager) *wants people who are committed to befriending*".

7.4.4.2 *Making a difference*

Making a positive difference to someone else's life was a key theme discussed by volunteers. It helped volunteers to feel as though they were doing something worthwhile and rewarding which they themselves gained many positives from. Volunteers not only described how they enjoyed feeling appreciated by the carers and this helped them to feel good about themselves, but they also gained a sense of satisfaction from their role and this gave them a lot of pleasure:

> Alice: "*I do get a lot of pleasure and a nice feeling from helping someone else, especially carers who often have such a hard time of it. I kind of see myself as a carer for the carers*".

Volunteers talked about how rewarding it was to be making a positive difference to a carer's life and that this is a crucial aspect to them volunteering and continuing to volunteer:

> Chloe: "*I think you know it's also the fact that you're helping somebody, that's why you do it, you want to help other people...*"

Volunteers often described how helping someone else helped them to feel good about themselves and that this was strong reason for them deciding to volunteer. This occurred in a number of ways, from helping volunteers feel that their day is worthwhile by helping someone else, because the carer is so appreciative and receiving feedback from the carer about the positive difference they have made to their lives:

> Jack: "*...it's been very beneficial because when you help somebody who's having problems, it's a rebound effect and it can help you as well, it makes you feel your day is worthwhile*".

Connected to the sense of feeling good by helping others, volunteers talked about how they gained a sense of giving something back, not only to society, but also to the services from which they had received support from when they were caring:

> Harry: "*Well it gives me a sense of doing something for people who are less fortunate and you do feel as though you're doing some good...giving something back to society*".

7.4.4.3 Burden on volunteers

Whilst volunteers were mostly positive in how they described their experiences of supporting carers, some talked about how it could, at times, be challenging. This not only related to the responsibility of seeing the carer at the same time every week, but also to being able to deal with other people's problems as well as their own. For example, being able to deal with some stressful situations they encounter during volunteer mentoring sessions. One volunteer described how she finds it stressful when carers become emotional:

> Jack: "*Well when people cry in front of you, you just need to be a patient listener and just to hear other people's problems, but it can be quite stressful*".

However, a male volunteer suggested that the conversations they had were fairly superficial, but that he might find it affects his emotions if the topics discussed were of a more emotive nature:

> Harry: "*...the conversations don't get too deep, so I don't find it depressing myself*".

One way in which volunteers were able to keep distance between themselves and the carers in order to reduce the potential burden on themselves was by maintaining adequate boundaries. Some volunteers described how sticking to boundaries helped them not to get too involved which helped them to take care of their own feelings:

> Emily: "*I think one of the negatives is- I don't think it's a negative, but I think whilst one becomes very attached and engaged in someone's life, one has to remember where the boundaries are about how involved you are*".

Other volunteers talked about how training helped to remind them about the importance of keeping boundaries with the carers:

> Elizabeth: "*The boundaries were good, but without sounding conceited, it was kind of common sense, and as I've been a volunteer on and off all my life I kind of did know what they were saying. But it was good to be reminded*".

However, volunteers also talked about how often it was a matter of personal judgement about how rigidly to stick to boundaries with carers. For example, one volunteer described how, despite being told by the service manager not to give her phone number to carers, she would still occasionally do this if she felt she could trust the carer:

> Chloe: "*…you know in your own mind who's going to bother you constantly and who isn't*".

One way of potentially reducing the potential stress or burden on volunteers was the provision of adequate training and to engage in supervision. Those volunteers without prior caring experience placed greater emphasis on training so they were able to pass on information they have learned to carers and to have a greater understanding of the impact dementia can have on families. Other volunteers described how supervision gave them the opportunity to discuss problems or challenges with the service managers and pass on issues carers were having which they felt unable to resolve:

> Ngozi: "*Yes it's very useful because I'm able to communicate back to my manager where I may be having issues and if it's not going on well…*"

However, not all volunteers placed an emphasis on training and supervision, with some explaining that they had learned enough from their previous caring experiences. Another volunteer described how having regular training or supervision would be a barrier to him volunteering due to time constraints, but he would value face-to-face meetings with the service manager if offered:

> Mark: "*I guess one good thing would be to meet with them, even if only once a year just to see how things are going*".

7.4.4.4 *Part of a bigger picture*

Whilst volunteers talked about how they felt volunteer mentoring had a positive effect on carers' lives, a theme which emerged was that it was only part of a bigger picture in providing adequate support for carers. For example, some volunteers would talk about how volunteer mentoring was not the right type of support for all carers. Some volunteers also talked about how carers suggested to them that weekly support could become intrusive or that they did not have adequate time to see the volunteer. There were also those carers who needed more intensive and targeted support which volunteer mentoring was not able to provide:

> Abby: "*…one lady said she was going to drive her car into the river…she said it to me twice and I thought well I don't think she's ever going to do it, but I passed it on because I thought 'well she might get to that stage'…but some people you can't help at all basically*".

Some volunteers explained how volunteering had enabled them to see the bigger picture regarding their own lives. For example, one volunteer highlighted how helping people through volunteering has helped her to value her own life more and that she feels happier because of it:

> Alice: "*It's had a big impact on me. I really value my life more these days, I mean I know I have quite a boring life in many ways but when I get home from seeing her I really think that it's better to be like I am… than struggling along like her, it must be so hard. I feel much happier and positive about life in general since I started*".

Similarly, another volunteer talked about how seeing someone else struggle has helped him put things in perspective:

> Mark: "*I think doing this befriending has really helped me see that life is short, you know. We're not here forever and there are more important things in life to worry about*" .

7.5 Quantitative and qualitative data synthesis

7.5.1 Integration of the qualitative and quantitative findings from carers

This section synthesises the quantitative and qualitative findings from carers. The findings for the effects on emotional health, loneliness and social support are compared and contrasted between the different types of data and are presented in Table 26.

Along with the data integration, the potential impact on the carers receiving volunteer mentoring services is also summarised (Table 26). Overall, the findings are largely complementary, with the qualitative findings expanding and helping to understand the initial quantitative results.

With regard to the dimension of emotional health, quantitative results showed no improvement in depression and anxiety. It could be argued volunteer mentoring has little impact in this area. However, the qualitative findings illustrated how the carers said they gained emotional support from volunteers and this was perceived to prevent an emotional decline. With regards to the dimension of loneliness, the levels of loneliness reported in the longitudinal questionnaire remained unchanged over time. However, the analysis of the semi-structured interviews demonstrated that carers felt that volunteer mentoring meant there was someone there for them and that they had something to look forward to. Concerning the dimension of social support, the data integration showed how volunteer mentoring can be a source of social support for carers. The statistically significant difference in perceived social support from 'significant others' between baseline, three months follow up, was confirmed by carers taking part in the qualitative phase. They perceived volunteer mentoring can help them be networked into other services and help them to cope better with their caring role.

Table 26. Merging quantitative and qualitative findings in a mixed methods matrix

	Quantitative results (p values)	**Qualitative findings (relevant themes and illustrative quote)**	**Data synthesis**	**Impact**
Emotional health	Depression: $p = 0.79$ Anxiety: $p = 0.78$	Subtheme 7.4.3.2 (Theme 7.4.3) sustaining emotions David. "*…it gives you a lift then and then after a few days I might have gone back to a…lower level of…umm…it's like a…less happy mood, but then I look forward to seeing him again*"	Qualitative findings backup quantitative results that volunteer mentoring had little lasting positive effect on emotional health. It did however keep carers supported and possibly prevented emotional decline.	Whilst not offering improvements in mental health, carers often gained emotional support from the volunteers and carers perceived this to prevent emotional decline. However, the support needed to be on a regular basis and a potentially long-term basis in order to help keep carers emotionally supported.
Loneliness	$p = 0.19$	Theme 7.4.3, someone there just for the carer Laura. "*…it's just something to look forward to. Even if you've got nothing else at least I know I've got that, you know*"	It would be expected from the lack of statistical significance in improvements in loneliness from the quantitative phase (assuming they were lonely to begin with), that carers would report feeling lonely despite the added support. However carers reported feeling less alone and some had made friends with the volunteers.	Volunteer mentoring may not reduce the loneliness carers feel on a day to day basis, but it gives them something to look forward to and they expressed how they found it reassuring that someone was there for them.

Perceived social support (from a significant other)	$p = 0.013$ (between baseline and three months)	Theme 7.3.3: carers feel listened to, and Theme 7.3.4: someone there just for the carer Henry. "*…umm I feel part of something, if I've got a problem…rather than just a loner…I suddenly felt as if someone's gathered me in*"	Quantitative results showed statistically significant improvements in perceived social support from a 'significant other' between baseline and three months. This was also shown in the qualitative findings, that carers felt they were no longer socially isolated and were now supported by the volunteer.	Volunteer mentoring is an important source of social support for some carers. Carers received advice and information, were networked into other services, expressed their emotions and talked about their concerns. This can help keep carers supported and enable them to cope better with the challenges of their caring role.

7.5.2 Integration of qualitative findings from carers and volunteers

Table 27 shows where the themes which emerged from the qualitative data from carers and volunteers converge in many respects. For example, the aspects of volunteer mentoring value were related to how volunteers perceived bonds were developed. These included experiential similarity, the volunteer characteristics and having common interests. Emotional support, coping with challenges and social inclusion were facilitated by carers being able to discuss challenges and the volunteers being able to listen effectively. Finally, sharing and mutual benefits were reported by both carers and volunteers. Carers described reciprocity of support, whilst volunteers reported benefits for themselves through the act of helping others.

Table 27. Merging of qualitative findings from carers and volunteers

Carers	Convergence	Volunteers
Aspects of volunteer mentoring carers value	• Experiential similarity • Volunteer characteristics • Common interests	Developing a bond
Carers feel listened to Someone there just for the carer	• Emotional support • Coping/getting through difficult situations • Social inclusion	Someone for carers to talk to
Reciprocity of support	• Sharing • Mutual benefits	Helping themselves through helping others

7.6 Summary of main findings

This mixed methods research furthers knowledge regarding the impact of volunteer mentoring for carers of people with dementia. It has a number of implications surrounding how best to support carers and volunteers using these services. Volunteer mentoring was seen to be an important source of emotional and social support for carers. This was facilitated by the volunteers' experiential similarity and the common interests they shared. Volunteers also reported the benefits they received from volunteering. These led to mutually beneficial relationships with a 'two-way' flow of support. By using a mixed methods approach it was possible to build a more comprehensive understanding of the impact of volunteer mentoring on carers than either quantitative measures or qualitative interviews would have provided alone. This is evidenced by the quantitative results showing little impact on carers, but the qualitative findings showing how carers value the support. However, previous research has shown discrepancies when reporting quantitative and qualitative findings (e.g. Greenwood et al. 1999). For example, as will be discussed in Chapter Eight, it could be argued that volunteer mentoring does not impact on mental health, but keeps carers emotionally supported, in which case one could argue it cannot be justified to use rating scales alone in understanding the impact of these services.

Despite lack of improvements in mental health and loneliness, as measured by the quantitative scales, this study has shown that volunteer mentoring is perceived as a valuable source of emotional and social support for carers and volunteers. However, it was also shown how volunteers perceived volunteer mentoring to be ‘part of a bigger picture’ to supporting carers of people with dementia, highlighting the importance of service diversity and flexibility. This was also suggested by the Healthbridge Report (Clarke et al. 2013), where it was shown not all carers found peer support useful and that it should be considered alongside other support services.

7.7 Conclusion

This marks the end of Phase Two of this research. Overall, it was shown that volunteer mentoring aided carers by way of sustaining emotional health and reducing social isolation. It helped them to cope better with caring challenges and helped them to continue caring through feeling supported. Finally, it was shown how volunteers also gained emotionally and socially from being volunteer mentors. Next, Chapter Eight discusses the findings of Phase Two in relation to Phase One. It also discusses the findings in relation to previous research and the implications these have for policy and practice.

8 Chapter Eight: Discussion and conclusions

8.1 Introduction

This research examined the impact of volunteer mentoring (befriending and peer support) on carers of people with dementia and volunteer mentors and found some evidence that it is an important source of emotional and social support for carers. English health and social care policy, described in Chapter Two, advocated the need for these services and suggested that volunteers were best placed to help deliver the interventions (DoH, 2009). However, there was a limited evidence base underpinning these policies (Chapter Four). The research questions and aims were informed by the two candidate theoretical frameworks - Homophily Theory and Social Exchange Theory (SET). The research questions addressed the need to understand the social and interpersonal perspectives to the successful development of volunteer mentoring relationships and included two phases. Phase One comprised of a systematic literature review (Chapter Four) and a survey of volunteer mentoring services (Chapter Five). Phase Two (Chapters Six and Seven) utilised a sequential explanatory (Creswell & Plano Clark 2011) mixed methods design, adopting a pragmatic approach to gain an in-depth understanding of the impact of these services and how carers and volunteers experienced the support.

This chapter discusses the findings from the synthesis of evidence from the two phases. As described previously, the five research questions were:

1. What is the range of volunteering mentoring services in England offered to carers of people with dementia?
2. What do the processes underlying volunteer mentoring involve?
3. What types of relationships do carers of people with dementia and volunteers form?
4. What is the evidence for the impact of volunteer mentoring for carers of people with dementia?
5. What are the volunteers' experiences and perceptions of volunteer mentoring?

This chapter addresses these questions in turn and then considers the strengths and limitations of the research overall. It concludes with the research strengths and limitations, and the researchers' reflections surrounding data collection and analysis.

8.2 Research question one: What is the range of volunteering mentoring services offered to carers of people with dementia?

Chapter Five showed the range of volunteer mentoring services offered to carers of people with dementia varied. More service managers operating befriending services (six) took part in the survey than either peer support (two) or mentoring (one). These services primarily offered face-to-face support (five) as opposed to telephone (three) or a mixture of the two (one). All services which assisted with the recruitment of carers for Phase Two of this research offered primarily face-to-face support. The majority were befriending services (six befriending services and one peer support). The recruitment of more befriending services over peer support for this research could reflect that this is the preferred model of volunteer mentoring in England, leading to more of them being commissioned. However, as will be discussed later in this chapter, befriending may not be the best option for carers who would benefit from the experiential similarity of peer supporters.

Five of ten volunteer mentors who took part in Phase Two of this research were former carers of a person with dementia. Former carers described experiential similarity as important in forming bonds with carers. Those without former caring experience could also perceive the potential benefit this experience could offer current carers, in terms of sharing how they coped with similar experiences, and the provision of advice and information. This contrasts to the view of experiential similarity service managers and volunteer coordinators held (Chapter Five). Only one manager operating a befriending service described it as essential for volunteers to have. A further three commented it was preferable and the remaining five reported it was unnecessary for volunteers to have former caring experience. As will be discussed later in this chapter, Phase Two of this research found experiential similarity was an important part of volunteer mentoring relationships.

This research has shown carers of people with dementia are offered a variety of forms of volunteer mentoring. The processes by which volunteer mentoring works, the impact it has on carers and the experiences of the volunteers will now be discussed. This will enable conclusions to be drawn on the most important aspects of volunteer mentoring for developing and maintaining successful volunteer mentoring relationships.

8.3 Research question two: What do the relationship processes of successful volunteer mentoring involve?

Both carers and volunteers discussed the importance of experiential similarity in developing bonds; however similarity on other dimensions (age, gender and common interests) often initially brought carers and volunteers together. Integration of qualitative findings from carers and volunteers showed convergence on two themes supporting the significance of similarity in volunteer mentoring relationships:

- Structural similarity (demographic characteristics)
- Experiential similarity

8.3.1 Structural similarities

Similarity, both in shared structural (also referred to as demographic) characteristics and experiential similarity were highly valued by carers and deemed important by volunteers in terms of developing bonds and trusting relationships. The analysis suggested that structural similarities facilitate the forming of bonds by which successful volunteer mentoring relationships develop, this argument is developed below.

Similarity in structural characteristics was found to be an important initial consideration for carers. For example, both gender and similarity in age were mentioned as factors when initially asking for support from a volunteer. Female carers often reported requesting female volunteers. The reasons for this were not always well articulated by the carers. However, some female carers and volunteers said they would feel uncomfortable if a male were to come into their home because they felt it could be inappropriate. This was also found in the survey (Chapter Five), where service managers reported female carers would often ask to be matched with female volunteers. This could be explained by carers finding it easier to talk about emotionally difficult topics to someone of the same gender (Suitor et al. 1995). It is therefore important to point out that experiential similarity, whilst an important priority for carers, was not the only concern when seeking a volunteer mentor.

Male carers did not report requesting male volunteers. This could be due to a number of reasons, including not feeling it necessary to have volunteers of the same gender in order to feel supported or not wanting to discuss difficult topics regardless of the volunteer's gender. Prior research has shown that male carers tend not to seek out as much practical and emotional support as female carers (Brown et al. 2007). There are several possible explanations for this. For example, some research has suggested that they have differing expectations of formal and informal support (Coe & Neufeld, 1999) and female carers experience greater emotional distress (Hepburn et al. 2002; McDonnell & Ryan, 2014). Other research has shown that male carers find talking about difficult topics easier with other males. For example, Harris (1993) reported that male carers wanted to talk with other men as they described finding it easier talking to someone of the same gender about personal topics, such as personal care and intimacy. However, it is important to note the small number of participants who took part in Phase Two of this research and that on occasion males also reported being able to share difficulties as important. Further research on carer gender differences in relation to the perceived importance of experiential similarity is therefore warranted.

Being matched to volunteers of a similar age was also important to some carers. This was partly due to carers and volunteers expecting to have more interests in common if they were a similar age, which carers explained helped them to develop bonds faster. Volunteers were divided in their views as to the importance of being a similar age to carers. Some drew on the same reasoning as carers, such as more common interests and bonding faster, whereas other volunteers reported that in their view that being a 'mature' person was sufficient. The volunteers' views support those shown by Suitor et al. (1995) that age was not a predictor of the providing of emotional support. However, given the importance of matching based on age reported by carers in the current research, it is argued that service managers operating similar services should consider this as part of the matching process.

The importance of matching volunteers to support recipients based on these initial similarities has been reported elsewhere. For example, in a study investigating befriending for isolated older people, Andrews et al. (2003) demonstrated how matching was "*...an important first step to relationship building*" (p. 354). This was also an important aspect described by managers and volunteer coordinators in the findings from the survey (Chapter Five). Whilst acknowledging the importance of initially matching carers and volunteers on structural similarities, the current research argues that carers of people with dementia need contact with volunteers who have been through similar caring experiences in order to develop stronger relationships.

8.3.2 Experiential similarity

Both carers and volunteers reported the importance of experiential similarity in the development of supportive and trusting relationships. Previous research conducted in the United States revealed experiential similarity to be an important aspect to peer support for carers of people with dementia (Pillemer & Suitor, 2002) and be more indicative of who is likely to be a source of social support than structural similarity (Suitor et al. 1995). However, the current research goes further by providing candidate theories to explain how and why experiential similarity is important. Carers reported that they needed to form trusting relationships with volunteers in order to feel safe enough to express their concerns. Whilst there were other factors which were important to both carers and volunteers in forming trusting relationships, such as having common interests and other volunteer characteristics, experiential similarity was described by carers as most valuable and they perceived it to enable the development of bonds. Further, experiential similarity was considered to lead to a number of other important outcomes for carers. For example, the advice and information volunteers gave based on their own experiences, led carers to report feeling more able to cope with challenging situations. This is supported by Stewart et al. (1998) who found in their study of peer support for carers of stroke survivors that ‘peer visitors’ offering emotional, informational, and affirmational support to carers resulted in enhanced coping ability.

The perception of the importance of experiential similarity was also shared by some volunteers, who felt they were better able to support carers given their past caring experience. The sharing of information and advice from the personal lived experiences of the volunteers also helped carers put difficulties in perspective and assisted carers in coping. Similar findings relating to past experiences and improved carer coping ability during difficult life events have been shown by Greenwood and Habibi (2014). In addition, volunteers without caring experience could perceive how it could be beneficial for carers if they had successfully been through similar situations.

The importance of experiential similarity for the development of empathy and understanding is supported by the qualitative findings, with carers reporting the importance of talking to someone who understood their situation and who listened to them without passing judgement. This has also been shown in previous research, with experiential similarity of volunteers enabling carers to discuss difficulties (Suitor et al. 1995), gain empathic acceptance (Veith et al. 2006) and exchange information (Keyes et al. 2014). Further, Pillemer and Suitor (1996) showed how those carers with larger networks of people with experiential similarity had lower depression scores. They argued the benefits of associating with others with experiential similarity were greatest among carers who reported suffering the most stress. The current research goes further, arguing that the mechanisms of experiential similarity are related to sharing personal experiences between carers and volunteers, and that this builds trust and the development of an environment within which to safely express negative emotions.

There are gender differences in the perceived importance of experiential similarity. Suitor and Pillemer (2002) showed how experiential similarity had little impact on patterns of social support for male carers. This corroborates qualitative findings from male carers in the current research. Male carers often talked about how they valued characteristics of the volunteers other than experiential similarity, for example similar interests, socialising outside their homes, and being able to play games or engage in physical activities such as sports. For female carers these aspects to volunteer mentoring were considered less important compared to being listened to and being able to express their emotions.

From the current research it is not possible to comment on whether volunteer mentoring would benefit new carers more than those with more experience, as the majority of carers who took part had already been caring for a year or more. However, Pillemer and Suitor (2002) suggested the importance of having, what they call 'similar associates' with experiential similarity, as part of a support network for carers. In particular they noted benefits when going through stressful life events, such as becoming a 'new carer'. It could be argued that when carers are first identified (for example, when a person with dementia is diagnosed) they should be given the opportunity to be networked with a volunteer mentor with previous caring experience.

There is a link here with the survey (Chapter Five) in terms of the perceived need for matching. Service managers explained how they believed that matching was often essential for building trust and forming stronger links between carers and volunteers. However, managers also reported matching carers and volunteers based on 'gut instincts' about who they thought would 'get on' well. The findings from Phase Two here suggest that matching on gender and age were important aspects in order to enhance trust. It also resulted in a higher likelihood of common interests and females potentially finding it easier to talk about difficult topics with volunteers of the same gender. Other than these two structural similarities, extensive matching criteria were not perceived as essential for carers. Another important factor was experiential similarity, which carers and many volunteers discussed as crucial to the development of successful support relationships. This, coupled with the findings that experiential similarity was critical for the bonding of carers and volunteers, may go some way to explaining the poor volunteer retention reported by service managers (Chapter Five). Further issues which could potentially affect volunteer retention are discussed in sections 8.4 and 8.5.

8.3.3 Homophily Theory

An interrogation of the above findings in relation to Homophily Theory helps explain the importance of similarity in the successful formation of volunteer mentoring relationships. McPherson et al. (2001) showed how people's social networks tend to be homogeneous, with ethnicity or race being the strongest predictor of successfully forming social relationships. These characteristics were followed in importance by age, religion, education, occupation and gender. It was also shown that relationships between dissimilar people (in relation to the above characteristics) tend to dissolve at a higher rate. However, this research suggests that this is less important with regards to volunteer mentoring relationships for carers of people with dementia. Carers here valued experiential similarity over types of shared structural similarity and this is supported by Sabir et al. (2003) who argued that only the shared experience of caring was a predictor of the development of successful relationships between carers and peer supporters. However, this was not always the case, with female carers in the current research often asking for female volunteers and other carers suggesting they would have more in common with a volunteer of a similar age. Nonetheless, given the perceived importance of experiential similarity, this research suggests that strong relationships between carers and volunteers are less likely to form if similar only on parameters such as age or gender, without there being a shared experience of caring.

In summary, these findings support the argument by Thoits (1986) that experiential similarity is the most important aspect of the support process, as it enables the development of empathic understanding. However, the findings reported here go further by explaining how experiential similarity can lead to mutually beneficial, trusting relationships which strengthen bonds and facilitates the discussion of difficult topics.

8.4 Research question three: What types of relationships do carers and volunteers form?

Volunteers talked about how reciprocity and mutual benefit were key aspects to further strengthening bonds between themselves and carers and explained how there was often a 'two-way' flow of support. Carers also reported that the sharing of personal information which takes place between themselves and volunteers was central to the development of volunteer mentoring relationships. These are now discussed below in detail.

8.4.1 Reciprocity and mutual gain

With the process and development of volunteer mentoring relationships initially led by structural and experiential similarities, the types of relationships carers and volunteers formed were based on reciprocity and mutual gain. It is hypothesised that this is the final element stage in the process by which mutually beneficial volunteer mentoring relationships develop. If one of these stages is missing, it is argued that successful volunteer mentoring relationships are less likely to develop. The stages of this process are illustrated diagrammatically in Figure 9.

Volunteers talked about developing mutually beneficial relationships as a reason for entering into volunteer mentoring, whilst carers also discussed thinking about wanting to provide support to the volunteers. This 'social exchange' was an important factor not only for volunteers to feel they were benefitting from giving support, but also for further developing trust and deepening connections to carers which enabled sharing of personal information. It is argued that this is the final part of the process for the successful development of mutually supportive carer and volunteer relationships and is highlighted in Figure 10. This research argues that the positive impact of volunteer mentoring for carers becomes evident when mutually beneficial relationships begin occurring. These impacts are described in detail later whilst answering research question three.

Investigating the factors which encourage volunteers to give their time to help someone else is important in understanding how to recruit and retain volunteers. Previous research has shown that whilst there are elements of altruism, volunteers are also often keen to receive something out of the support, for example if they find it rewarding (Fyvie-Gauld & de

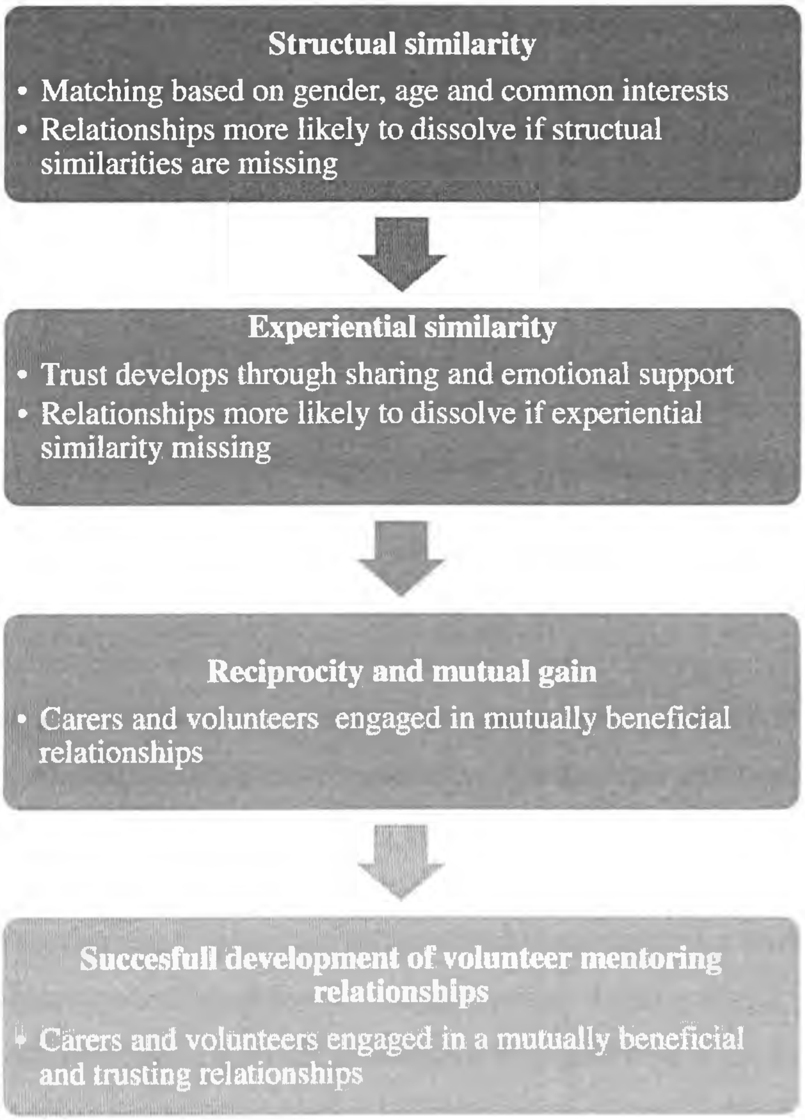


Figure 10. Processes by which successful volunteer mentoring relationships develop.

Podesta, 2007). Similar findings are reported here, with volunteers reporting the benefits they received from giving their time. One positive aspect often described by volunteers was how they often made friends with carers which subsequently positively impacted on any loneliness, social isolation or low mood they may have been feeling. This has been reported previously, with Prouteau and Wolff (2008) suggesting that the opportunity to make friends is a primary driver for people when deciding to volunteer. Whilst the primary motive of the volunteer mentors is providing assistance to carers, taking in to consideration the needs of volunteers is important for volunteer retention (Ross et al. 1999; Warburton et al. 2001; Wilson, 2000). Further, making sure that people who are currently volunteering feel they are benefitting and can see the positive impact they are having on the carers, could be a way of helping to retain volunteers.

8.4.1.1 Social Exchange Theory

The importance of reciprocity and mutual gain can be understood with reference to Social Exchange Theory (SET) (Emerson, 1976). In particular, the findings link to an explanation of social exchange reported by Cropanzano and Mitchell (2005, p. 890):

> "*Social exchange comprises actions contingent on the rewarding reactions of others, which over time provide for mutually and rewarding transactions and relationships*".

The present research argues that the exchange of support between carers and volunteers is an important factor that makes for beneficial volunteer mentoring relationships, with both carers and volunteers supporting each other. It is also argued that if social exchange is missing in volunteer mentoring relationships (in particular peer support) this is likely to lead to a less successful intervention. This is supported by Krause et al. (1992), who showed that without reciprocity in formal volunteering roles, it is unlikely to lead to the positive effects, such as improved well-being. The authors go on to argue that volunteers strive to gain a sense of balance in exchanges, as most people do in any other informal social networks, and that support given is likely to want reciprocating. The importance of social exchange in volunteer mentoring relationships is further supported by Palo Stoller (1985), who suggested that the ability to reciprocate support was more important than the level of need for support in boosting morale in older people's informal networks. Therefore, it is hypothesised that volunteer enjoyment, satisfaction and therefore retention are likely to be highly dependent on there being some social exchange between carers and volunteers.

A further aspect identified here was the desire for carers to give something back to the volunteers, despite acknowledging the volunteers were primarily there to help them. This has been shown previously in research examining social exchange in relationships, with the suggestion that those receiving help felt the need to give something back (Homans, 1958). It was also identified in research investigating peer support for carers of people with dementia (Greenwood et al. 2013). Further, other research has shown if those receiving the help or assistance are able to reciprocate support, then more trusting, mutually beneficial and binding relationships developed over time (Cropanzano & Mitchell, 2005; Emerson, 1962; Hogan et al. 2002; Molm et al. 2000). Therefore, it is argued here that volunteer mentoring services which encourage the development of mutually beneficial relationships between carers and volunteers, are more likely to improve outcomes for carers and increase volunteer retention.

8.5 Research question four: What is the evidence for the impact of volunteer mentoring on carers?

Research question four aimed to establish the impact of volunteer mentoring on carers. The systematic review (Chapter Four) found little evidence for the impacts of these services on carers. However, the survey (Chapter Five) showed these services aimed to increase social integration, reduce loneliness and offer emotional support.

Three self-report questionnaires were administered which investigated depression and anxiety (HADS; Zigmond & Snaith, 1983), loneliness (UCLA loneliness scale; Russell, 1996) and perceived social support (MSPSS; Zimet et al. 1988). Whilst no statistically significant improvements were found for the mental health of carers, they did describe in subsequent interviews how the interactions with the volunteer mentors allowed them to release built up emotions. They also reported that due to the stressful nature of caring for people with dementia this emotional release was needed frequently to avoid a build-up of emotions. Therefore, the positives carers reported and the development of successful volunteer mentoring relationships may not lead to improved outcomes. However, other forms of support for carers of people with dementia have demonstrated a change. For example: psychoeducational, counselling, support groups and Admiral Nurse visits (Bunn et al. 2015; Cooke et al. 2001; Sörensen et al. 2006) have all been shown to decrease either depression or anxiety.

The findings of this research on the impact on carers' mental health will now be discussed below.

8.5.1 Impact on mental health

Carers of people with dementia have an increased risk of developing emotional difficulties compared to non-carers (Etters et al. 2008; Kim et al. 2011; Leggett et al. 2010; Mahoney et al. 2005; O'Shea, 2003; Pinquart & Sörensen, 2003). Whilst volunteer mentoring interventions in other populations, such as females with depression (Harris et al. 1999) and people with schizophrenia (Sensky et al. 2000), have been shown to reduce the impact of emotional difficulties, their effective use for carers of people with dementia is unclear (Charlesworth et al. 2008). The results of Phase Two of this research showed no statistically significant impact on either anxiety or depression for carers of people with dementia. This supports the findings of previously reported studies (Charlesworth et al. 2008; Pillemer & Suitor, 2002) which reported a lack of positive impact on depression or anxiety of volunteer mentoring on carers of people with dementia. However, previous studies of volunteer mentoring interventions have found positive effects on mental health of carers of people with other conditions. For example, when investigating the impact of group telephone peer support, Winter and Gitlin (2007) found female carers over the age of 65 had statistically significant reductions in depression after six months. It should be noted the telephone groups were facilitated by trained social workers, which may possibly explain the reductions in depression as opposed to volunteers delivering peer-to-peer support with no formal training in counselling skills.

The carers in this research did not specifically talk about the importance of seeing the volunteers face-to-face. However, previous research involving forms of technology without face-to-face meetings, such as teleconferencing, found that some carers felt uncomfortable in talking to each other (McHugh et al. 2012). Using this method of delivery could be a potential barrier to the sharing of personal information and demonstrates the importance of face-to-face interactions for some carers.

These findings give strength to those reported in the systematic review (Chapter Four) concerning a lack of impact of volunteer mentoring services on carers' mental health. However, in the time since the review was conducted in January 2013, further studies involving carers of people with dementia and volunteer mentoring have been published. One of these (Greenwood & Habibi, 2014) reported statistically significant improvements in carer depression and anxiety as a result of receiving mentoring. Differences between befriending, peer support and mentoring could possibly explain these findings. The mentoring intervention investigated by Greenwood and Habibi (2014) was structured, with mentoring sessions taking place for a set time once a week for between six and 12 weeks. It is possible that this more structured approach, when compared to befriending and, to a lesser degree peer support, offers improved mental health outcomes for carers.

The quantitative results indicate volunteer mentoring is not an effective intervention at reducing emotional difficulties in carers of people with dementia. Further, the qualitative findings also suggest that volunteer mentoring had little lasting positive effect on emotional health. However, regular contact with the volunteer mentors was perceived by carers as providing emotional support and preventing emotional decline. Being able to talk to the volunteers and share their feelings, led carers to feel emotionally supported. This in turn enabled them to cope with and get through difficult situations to continue caring, but it was needed regularly in order to keep their emotions stable and prevent a decline in their mental health. Similar views were expressed by the volunteers, who perceived the emotional gain for carers to be the regular release of built up emotions. Both carers and volunteers emphasised the importance of being listened to and sharing feelings in sustaining carers' emotions. With English policy focusing on the prevention of health problems (DoH 2008) and promoting well-being (Care Act, 2014), volunteer mentoring could be offered to carers soon after they are identified, rather than carers searching out support services when they are already suffering from mental ill health.

8.5.2 Impact on loneliness

Higher levels of reported loneliness have been correlated with increased incidence of mental illness, particularly depression (Cacioppo & Hughes, 2006; Liu et al; 2014). Previous research has highlighted loneliness as an area of concern for carers of people with dementia, with increased loneliness correlated with increased depression (Beeson, 2003). The current research found no statistically significant difference in loneliness and is in-line with findings reported by Charesworth et al. (2008) and also supports evidence reported by Dickens et al. (2011) that one-to-one social support interventions have limited impact on reducing loneliness. The lack of statistically significant improvements on loneliness have been shown elsewhere in other support types, such as support groups and counselling, for isolated older people (Cattan et al. 2005). However, mean baseline levels of loneliness reported here of 49.13 are higher than that reported by Beeson (2003) for carers of people with dementia at 37.35, and higher than the elderly population in general (31.51), (Russell, 1996). This could indicate carers who are experiencing the most loneliness and isolation are more likely to access volunteer mentoring services.

The qualitative finding from this research support those found by Stewart et al. (2006) for telephone peer support. Carers of people with dementia reported less loneliness through having someone to talk to. As reported in Chapter Seven, volunteer mentoring may not have reduced the loneliness carers feel on a day to day basis, but it did give them something to look forward to and they described how they found it reassuring that someone was 'there' for them. Previous research has shown companionship (Rook, 1987) and friendships (Hall-Elston & Mullins 1999) to be protective factors against loneliness in other populations. Therefore, it is argued that the formation of friendships is an important aspect of volunteer mentoring for some carers, and it should be encouraged by service providers where possible.

Carers here reported feeling less alone with their problems, but this did not necessarily lead to reductions in loneliness on the UCLA rating scale. Perhaps seeing a volunteer for approximately one hour per week is not enough to improve feelings of loneliness, especially if carers are often alone. However, given the trend for reductions in loneliness, it could be that one of the beneficial aspects of volunteer mentoring relates to increased social inclusion through carers being networked into other support services. Therefore, future longitudinal studies should assess the impact of volunteer mentoring on carers' social networks and how this potentially affects loneliness.

8.5.3 Impact on perceived social support

The use of mixed of methods has allowed greater in-depth exploration of the potential reasons as to why volunteer mentoring had a positive impact on perceived social support. The 'significant other' in this case is understood to be the volunteer mentor, with qualitative findings suggesting the importance of giving carers personalised support which can be tailored to their individual needs. However, the large number of other support interventions the participants were also accessing make it difficult to be confident about the impact of volunteer mentoring on perceived social support. It is possible the increases the carers reported were are least in part due to also accessing support groups (nine carers) or receiving assistance from an Admiral Nurse (six carers). Future studies may wish to exclude carers already in receipt of other social or statutory support interventions.

Carers of people with dementia are more socially isolated than non-carers (Brodaty & Hadzi-Pavlovi, 1990), with socially isolated carers further negatively impacted by the stressors of caring (Scharlach et al. 2001). The quantitative findings from the current research showed statistically significant improvements in perceived social support from a 'significant other' between baseline and three months. This is an important finding, as previous research has shown two-thirds of psychosocial or educational interventions aimed at carers of people with dementia do not improve social support outcomes (Cooke et al. 2001). Therefore, volunteer mentoring could be targeted towards those carers who are at greatest risk of becoming socially isolated.

The qualitative findings relating to social support corroborate the quantitative results with both suggesting improvements in perceived social support. Qualitative findings here showed that volunteer mentoring was perceived to be an important source of social support for some carers. Carers received advice and information, were networked into other services, expressed their emotions and could talk freely about their concerns with volunteers who they felt were there to listen to them and help them with their needs. Carers felt they were no longer socially isolated and now felt supported by the volunteer. Keyes et al. (2014) found that peer support for people with dementia and their carers led to friendships and a sense of belonging, which helped to reduce social isolation. This was facilitated by identification with 'similar others', commonality of experience and reciprocity of support. Similar findings were shown in the current research, with carers and volunteers alluding to making friendships with each other. According to service managers (Chapter Five) and volunteers, these friendships can last long after the volunteer mentoring intervention has ended.

The findings of this research add strength to the English government's emphasis on developing peer support and befriending services for carers in order to decrease social isolation (Yeandle & Wigfield, 2011). Similarities were found between the current research and the evaluation by Yeandle and Wigfield (2011). For example, here carers felt they had better access to information, were no longer isolated, found it easier to access leisure and employment opportunities, and gave them the feeling of 'having a life of their own'.

8.6 Research question five: What are the volunteer mentors' experiences and perceptions of volunteer mentoring?

Primary research was undertaken using semi-structured interviews to understand the experiences of volunteer mentors. Integration of the qualitative findings from carers and volunteers found convergence of themes. These themes related to carers' perceptions the importance of reciprocity in supporting each other and the perceptions of the volunteers receiving benefits through helping others. These findings are also discussed below in relation to background literature (Chapter Three) and the findings from the survey (Chapter Five).

8.6.1 Emotional and physical health

Previous research has suggested volunteering improves psychological well-being due to increased access to psychological resources (Musick & Wilson, 2003) and a sense of belonging and purpose (Piliavin & Siegl, 2007). The findings from this research add to the growing evidence of the benefits of volunteering, however, the benefits reported here are linked to the strength of the relationships the volunteers form with carers. For example, the more trust which develops as a result of experiential and structural similarity enables the volunteers to receive emotional support when discussing past memories. However, female volunteers more often reported discussing topics related to the distress carers were feeling, whilst male volunteers more often talked about playing games or sports with the carers, particularly befrienders. It is argued here that peer support offers both carers and volunteers a greater chance of reciprocating emotional support, whilst befriending potentially offers carers and volunteers social contact which may not necessarily result in the same depth of sharing and reciprocal support. Without experiential similarity, befriending relationships may dissolve more frequently or offer poorer outcomes than peer support. This has been reported previously (Cox, 1991), with volunteers with more experiential similarity more likely to develop lasting relationships with the person being befriended.

As with improved psychological well-being, research has shown how volunteering can maintain or slow physical health decline in older people (Lum & Lightfoot, 2005; Tang, 2009). In this research, volunteer mentors did not often discuss potential physical health benefits of volunteering, but carers explained how they felt the volunteers gained both mentally and physically from volunteering, in particular saying because it 'gets them out of the house' and keeps them active. Although there could be physical health benefits for some volunteers, it is difficult to draw inferences relating to the physical health benefits of volunteer mentoring and is worthy of further investigation.

It has been previously documented that many volunteers gain a sense of satisfaction, boost in self-esteem and a feeling of happiness from volunteering (Casiday et al. 2008, Thoits & Hewitt, 2001). Similar findings were found in this research, with volunteers describing looking forward to and enjoying seeing the carers. Volunteers talked about how it gave them a boost in self-esteem and in some cases reduced depression. As already discussed, this could partly be due to the two-way nature of the support, with volunteers often being able to express their worries and concerns with carers, including the opportunity to talk about difficulties with their own past caring experiences. However, whilst carers described how the volunteers may find it therapeutic to discuss painful memories, volunteers did not necessarily see this as potential benefit. For example, the sharing of difficult experiences, which helped to build trust and a rapport with the carers, could lead to feeling of sadness. Therefore, it is important that volunteers are given adequate training and regular supervision.

8.6.2 Enjoyment and making a positive difference

Making a positive difference to the carers lives and seeing how their help was valued by carers was important for the volunteers and was closely linked with satisfaction and decision making when deciding to continue volunteering. This has been shown previously, with volunteers suggesting satisfaction with their role was linked to seeing positive results of their volunteering (Low et al. 2007; Matsuba et al. 2007). Therefore, it is argued here that if volunteer mentors do not observe a positive difference they are making to carers' lives, their sense of satisfaction and enjoyment may be diminished. Further, this is linked to a previous research identifying volunteers' need to feel as though what they do matters. Piliavin and Siegl (2007) found that a sense of 'mattering' helps link volunteering to well-being. Mattering was described as being engaged with the world around you, feeling important to others and that people care about you. By seeing that they are making a positive difference to someone else's life, it could bring more importance to their own lives by doing something worthwhile and the belief that they matter to somebody else.

Volunteers were often those who had received a befriending or peer support intervention in the past and wanted to 'give something back to society' by volunteering now. This was also found by Manatschal and Freitag (2014), who showed how those who have received help in the past, might be motivated to 'pay this back' in the future. Previous research has also shown that the majority of people who volunteer find it to be an enjoyable experience (Pillemer & Suitor, 2002), with others (approximately 30%) suggesting it gives them the opportunity to form friendships (Low et al. 2007). However, being a volunteer was not without some difficulties.

8.6.3 Challenges for volunteers

Whilst on the whole volunteers described benefits to them being volunteer mentors, there were a number of challenges and difficulties reported. These challenges were often seen as a burden on the volunteers and a potential source of stress. For example, not knowing how to respond when a carer becomes emotionally distressed and the bringing back of painful memories from their own caring experience. The systematic review (Chapter Four) highlighted a lack of research on the impact of volunteering on volunteer mentors for carers of people with dementia. Whilst the current research and other studies before it (Burr et al. 2013; Cattan et al. 2011; Harris & Thoresen, 2005; Kahana et al. 2013) have shown there to be a number of consistently reported benefits to volunteering, the lack of understanding of the negative impacts on volunteers it worthy of further research. However, a recent study by Greenwood et al (2014) investigating peer support, reported similar findings to those reported here, with volunteers expressing challenges such as reliving difficult experiences, fear of rejection by carers and becoming emotionally drained. Given the stressors and strains placed on former carers supporting carers of people with dementia, future research is warranted to understand if these are barriers to volunteer recruitment and if there are any long-term impacts on volunteers.

Volunteers' views regarding training and supervision were mixed. Whilst many saw supervision as a way of accessing support, others felt that having to meet with the manager for supervision too frequently would be a barrier to volunteering due to time constraints. Similarly, when it came to volunteer training some felt it could be a barrier if it was too extensive and time consuming. However, those with no prior caring experience placed greater emphasis on training, potentially highlighting the need to understand the challenges of caring for a person with dementia.

The survey (Chapter Five) and the comments of volunteers from Phase Two suggest that service managers and volunteer coordinators were aware of the potential difficulties they faced. Volunteers commonly described how they were informed by managers of the importance of keeping boundaries with the carers in order to make sure they were not giving more support to carers than they felt they were able to. However, volunteers often made friends with carers which sometimes continued after the support intervention had ended, but they used personal judgement in deciding which carers to give their personal phone numbers and addresses. Qualitative findings also showed that developing friendships with the carers had a positive impact through reducing their own social isolation and loneliness.

8.6.4 Former carers

Whilst it has been documented that there is a void or gap in the lives of family members when caring comes to an end, little is understood about the experiences of former carers, particularly regarding the emotional and social losses which can occur (Cronin et al. 2015). Larkin (2009) argued how there can be a 'post-caring void' which can encompass feelings of grief and loss. In moving on from grief, former carers will try 'constructing a life post-caring'.

Former carers, mainly peer supporters, indicated volunteer mentoring was a chance to develop social contacts, boost physical and emotional health, and allowed them to develop mutually beneficial relationships. This has important implications for services in recruiting former carers. Firstly, by highlighting the potential benefits to former carers, namely that volunteer mentoring is an opportunity to develop mutually supportive relationships, may help their recruitment. Secondly, given that some former carers report feeling depressed (Carers UK, 2004) it could be argued that volunteer mentoring could aid their recovery and help to fill the 'post-caring void' (Larkin, 2009) and is worthy of further investigation. However, it also needs to be noted that this may not be appropriate for all former carers, especially as a number of peer support volunteers talked about difficulties resulting from their role. Most notably reliving painful and distressing experiences and finding it difficult to deal with the emotions of current carers were reported by some former carer volunteers. Some of the current carers said that they could not envisage reliving what they described as painful experiences by supporting others when caring ends. However, others did suggest they would potentially like to give something back and help those who are going through similar experiences. It is argued here that volunteer mentoring can offer some former carers the opportunity to develop friendships and improve their own health once their caring role has come to an end.

8.7 Differences and similarities between peer support and befriending schemes by intervention type

Whilst no differences were found by intervention type from the quantitative results, findings from qualitative interviews with carers and volunteers did highlight areas of variation. The most obvious difference was, by definition, that peer support requires volunteers to have had prior caring experience whilst befrienders may not. However, even those carers receiving befriending explained the importance of experiential similarity. This was also explored by befriending volunteers with no prior caring experience, in that they could see how experiential similarity may lead to improved support for carers. This could be a potential limitation of this research, as any positive impact of peer support could have been lost due to the differences which exist between the two forms of volunteer provided carer support. Future studies should include a larger sample of carers receiving all types of volunteer mentoring to unpick the differences between the services further and to understand if either offer better outcomes.

8.8 The researcher's reflections

Throughout the data collection process the researcher kept a reflective diary. This diary contained notes about the thoughts, feelings and the experiences of the researcher during the interviews. These reflections are described here in relation to the researcher's background and how these potentially informed the interpretation of the qualitative findings. Creswell (2013) argues reflexivity consisted of two parts:

> *"The researcher first talks about his or her experiences with the phenomenon being explored. This involves relaying past experiences through work, schooling, family dynamics, and so forth. The second part is to discuss how these past experiences shape the researchers' interpretation of the phenomenon".*

8.8.1 Reflecting on face-to-face interviews with carers

Interviewees' perceptions of the interviewer have been shown to influence interview interactions. For example, Richards and Emslie (2000) showed how the professional background of the interviewer can influence topics discussed. This was discussed with reference to the researcher in the current research in section 6.7. 11. His background working in the voluntary sector providing information and advice to people with dementia and their carers, could have potentially influenced how the participants perceived him and their expectations of taking part. However, this was not disclosed to participants, with the researcher informing them he was a PhD student.

The researcher's gender could have impacted on the type and variety of data collected. For example, Pollner (1998) reported female interviewers tended to obtain a higher number of reports of mental health issues from interviewees. Further, it has been suggested female participants may be more willing to share personal or sensitive information to female interviewers (Davis et al. 2010). Subsequently, carers who took part in this PhD research may not have disclosed the full extent of the difficulties they were experiencing to the male researcher.

8.8.2 Difficulties the researcher experienced and how these were overcome

This section explores challenges the researcher encountered when conducting face-to-face interviews with the carers. It focuses on the experiences of carers becoming emotional during interviews, carers taking part in research as a way of gaining social contact and considerations surrounding interviewing carers when the person with dementia can potentially hear the conversation.

During face-to-face interviews some carers became upset, with two crying when talking about sensitive topics. In this instance the researcher asked if they would like to take a break or continue with the interview another time. All carers indicated the wanted to continue with the interviews. The researcher showed his concern and offered support by offering to provide information they may need or to signpost them to community groups. Being empathic and showing interest in the distress a participant is experiencing was always placed above the collection of data.

The researcher became aware that some carers may have taken part as a way of gaining social contact. Before the interview, one carer (a female caring for her husband) talked about how she was looking forward to my visit as she rarely manages to leave her flat. She discussed how people do not visit when her husband (person with dementia) is there and she no longer has many friends. Further, she discussed being lonely and how it was nice to have someone to talk to when her husband spent fours hour per week in respite care. The researcher offered to provide her with the information of local community groups and gave her his work details should she need further information or advice.

During one visit the person with dementia was in the living room whilst the interview was conducted with the carer in the kitchen. The researcher felt uncomfortable with the possibility the person with dementia may over hear the conversation and the potentially difficult topics which would be discussed. This led the researcher to speak quieter than usual and the carer had to ask more than once for the question to be repeated.

The researcher became aware of the importance of the period of time after the interview had ended. It gave the researcher time to further explain the interview would be transcribed before being destroyed and it also gave the carers and volunteers an opportunity for carers to ask any questions they had about the research.

Many of these challenges discussed here were prepared for in advance when applying for ethics approval (Appendix 25). However, issues surrounding carers taking part as a way of gaining social contact and discussing sensitive topics when the person with dementia could potentially overhear, were issues identified throughout the process. These challenges should be considered when preparing future research involving carers of people with dementia and how they can potentially impact upon the quality of the data collection.

8.9 Strengths of this research

A strength of this research is its multiple phases addressing the questions from the different perspectives of key participants in peer to peer support and befriending schemes. The conclusions drawn from the systematic review (Chapter Four) and survey (Chapter Five) led to a clear understanding of research problems to be addressed and, ultimately, the use of the sequential explanatory design (Creswell & Plano Clark, 2011).

The mixed methods design in Phase Two combined the advantages of using both quantitative and qualitative approaches to provide more complete knowledge of the processes and impact of volunteer mentoring. It also offsets the weaknesses from each method (Mertens & Hesse-Biber (2012), for example, using quantitative methods alone would not have allowed for an exploration of how carers felt they were, or were not, benefiting from the support.

8.10 Limitations of this research

Whilst there are a number of strengths of this research, there are also weaknesses and the findings of this thesis need to be interpreted in context of its limitations. The potential limitations of mixed methods research has been discussed in Chapter Six, section 6.7. The debate over mixing methods and epistemological assumptions in a single research study has been the subject of much discussion (Onwuegbuzie & Leech, 2007). Further, there is no complete agreement of how to interpret conflicting quantitative and qualitative findings (Johnson & Onwuegbuzie, 2004). Conflicting findings are present in this research and highlight the complexity of combining paradigms in one research study which were not satisfactorily resolved through triangulation. For example, the disparity between quantitative and qualitative findings surrounding the impact of volunteer mentoring on carers' mental health.

The small sample size limits the power of the conclusions. However, this is offset by the strength of being able to synthesize the quantitative and qualitative data providing a more robust and comprehensive overview of the impact on volunteer mentoring for carers. The small number of carers recruited for the quantitative phase had implications when recruiting for the second qualitative phase. It was intended that purposeful sampling would be used based on scores from the quantitative scales, however too few carers took part to make this viable. With a larger sample of carers, recruitment for the qualitative phase could have been targeted to those carers who scored highest and lowest on the scales, equal number of males and females, and an even balance of those who were receiving either befriending or peer support. This could have furthered the understanding of the differences between the types of services and how and why they work or do not benefit some demographic groups of carers.

The lack of BME carers in this research affects its generalisability. All 19 carers enrolled at baseline described themselves as White British or White English. There are several possible explanations for this, but it may be a reflection of BME carers not accessing social support services more generally due to the perceptions they did not meet their needs or were not appropriate (Dilworth-Anderson & Gibson, 2002; Greenwood et al. 2015). Further, all but one of the volunteers described themselves as White British. It is impossible to know whether this is representative of the proportions of BME volunteer mentors and further research is required. If this a common percentage across all volunteer mentoring services it could show that there are unrepresentative samples of volunteers of ethnic minorities taking part or that volunteer mentoring is not appropriate for their needs. Recent research has shown that there are language, cultural and religious concerns among BME carers which affect participation in support services (Greenwood et al. 2015).

This research is therefore limited in its generalisability by failing to include more BME carers. Further, it did not investigate differences in carers' social class, educational attainment, sexual orientation or cultural differences. Future research should investigate if carers from minority groups face barriers in accessing volunteer mentoring or if it is appropriate for their needs. For example, lesbian, gay, bisexual and transgender (LGBT) carers may prefer further homophiliy of volunteer mentors of the same sexual orientation in order to facilitate development of their relationship.

The method of recruiting carers and volunteer mentors had limitations. Information packs were sent out to services for the managers or volunteer coordinators, who had previously agreed to assist with recruitment, to pass onto carers and volunteers. Selection bias could have occurred due to them only giving the information packs to carers or volunteers they felt might provide a positive description of their service. The lack of control may also have hindered the numbers recruited to the research. This was a difficult issue to overcome, as participant confidentiality was of paramount importance and it was not possible to work more closely with the services to gain access to carers' and volunteers' addresses to make contact with them directly.

It is possible that only the most mentally and physically healthy carers were able to take part. Had it been possible to recruit a more diverse sample of carers accessing these services, it could have resulted in carers who were more depressed or anxious at the start of receiving support taking part. This may have led to greater changes in mental health over the study period.

Research has shown that telephone interviewing is more suited to short and well-structured interviews (Fontana & Frey, 1994). Participants of telephone interviews are more likely to present themselves in socially desirable ways, be less engaged and cooperative with the interview than those taking part in face-to-face interviews (Holbrook et al. 2003). There are also issues surrounding anonymity and sensitivity. For example, some carers and volunteers may have been more forthcoming with sharing information when talking about sensitive topics over the telephone due to the added anonymity this provides. However, telephone interviews also limited the researcher's ability to recognise when a carer was becoming distressed and offer options to pause the interview. This is because telephone interviewing deprives researchers from seeing participants' non-verbal communication (Creswell, 1998). Recruiting carers of people with dementia to research studies through voluntary sector organisations has previously been shown to be challenging (Charlesworth et al. 2008). It is therefore the view of the researcher that not offering the option for telephone interviewing may have led to carers not taking part and their views not being represented.

It is possible that the use of validated outcome scales may not be focusing on the aspects of volunteer mentoring which are most important to carers. For example, Charlesworth et al. (2008) argued that depression may not be the most appropriate outcome measure for befriending and its most important benefits could have been missed. Future research should consider whether measuring reductions in depression scores as a primary outcome is most appropriate for identifying the success or failure of volunteer mentoring.

A final limitation surrounds the qualitative findings. As support was being provided by volunteers, carers may have over emphasised the positive aspects of volunteer mentoring due to not wanting to seem ungrateful or hurt the feelings of the volunteers (Greenwood et al. 2013). This potential overemphasis of the benefits may explain the differences in quantitative and qualitative findings, with carers more able to be honest on anonymised rating scales.

8.10.1 Strengths and limitations of the sequential explanatory design

The strengths of this design are based in its two phase sequential structure. This makes it easy to implement, in that only one data type are collected at a time (Creswell & Plano Clark, 2006). This design is also useful when researchers want to explore further quantitative findings, for example to purposefully sample participants to take part in the qualitative phase (Tashakkori & Teddlie, 2003). Despite the strengths to using this design there are potential methodological challenges and limitations (Ivankova et al. 2006). Methodological issues include justifying the weight given to each phase in terms of data collection priority, and implementation issues, such as when and how to integrate the quantitative and qualitative phases to answer the research questions (Ivankova et al. 2006). The main limitation of this design is the length of time it can potentially take to implement both phases (Creswell & Plano Clark, 2006; Tashakkori & Teddlie, 2003). For the current research, this is especially true, given that qualitative data collection was unable to begin until carers have completed the second set of questionnaires after three months.

8.10.2 Strengths and limitations of the thesis as a whole

Taken as a whole, this thesis has both strengths and limitations which will now be explored. Firstly, this thesis is limited in its generalisability, namely that it investigated volunteer mentoring schemes in England only. Further research is needed to explore if the findings reported in this thesis are relevant to the other constituent countries of the UK where health and social care provision is devolved. This thesis should be interpreted in light of its focus on social support for carers of people with dementia provided in Western high income countries. Whether the findings reported here are applicable to low and middle income countries or different cultures is unclear and requires further research. However, whilst the focus of the thesis is a limitation in relation to generalisability, it is also an inherent strength. Concentrating on the policies and volunteer mentoring interventions of one country has enabled this thesis to offer more focussed answers as to their benefits and outcomes they offer that population.

There has been a long history of discussion surrounding the use of the terms reliability and validity, with many suggesting they are more appropriate to quantitative as opposed to qualitative research (Golafshani, 2013; Morse et al. 2002). Since the 1980s, qualitative researchers have utilised methodological strategies to try and ensure rigor and trustworthiness of findings, for example, triangulating the findings; having more than one researcher involved in data analysis and including rich and thick descriptions of participants' accounts to support the results (Creswell, 2013 Lincoln & Guba, 1985; Patton, 2002). The researcher has reflected on his past experiences and assumptions which may have shaped his interpretation and approach to Phase Two of this research in section 8.8. However, when reflecting on the thesis as a whole, the interpretations of the findings is likely to have been influenced by the researchers' previous work experience in which a key outcome was to help carers of people with dementia become more socially integrated. The researcher could have potentially biased the findings of this thesis by not giving as much credence to the carers' perceptions which showed indifference to volunteer mentoring or those who had reported negative experiences of accessing the interventions. Nonetheless, efforts were made to avoid this, for example, with more than one researcher involved with data analysis (in both phases of the thesis), using semi-structured interviews with open ended questions and triangulating the findings from carers and volunteers in Phase Two.

8.11 Conclusions

This section explores the contributions this research has made to the literature and the implications for decision making for policy and practice.

This research investigated the impact of volunteer mentoring on carers on people with dementia and the experiences volunteers providing the support. Carers of people with dementia often experience social isolation and mental health problems due to the stress of their role. Voluntary or 'third sector' organisations are increasingly providing services with the help of volunteers to keep carers supported. With English government policy emphasising the development of peer support and befriending services for carers, this research aimed to explore, along with impact on carers, the mechanisms by which volunteer mentoring works and which aspects of the support provide the best outcomes.

This research has provided a valuable insight into the outcomes volunteer mentoring can offer both carers and volunteers, along with an understanding of the aspects which help carers and volunteers form mutually beneficial volunteer mentoring relationships. It is argued that without experiential similarity, carers and volunteers may not develop the level of trust necessary to form mutually beneficial relationships.

8.11.1 Contributions to knowledge

This was one of the first studies of its kind to investigate both the process of volunteer mentoring interventions and their impact specifically on carers of people with dementia. Much of the previous literature has focused on carers more generally (Dickens et al. 2011; Mead et al, 2010), other types of support for carers of people with dementia (Bunn et al. 2015; Cooke et al. 2001; Sörensen et al. 2006) or used primarily one method to investigate the various types of volunteer mentoring (Charlesworth et al, 2008; Pillemer & Suitor, 2002; Sabir et al, 2003; Stewart et al, 2006). The theoretical contributions and methodological contribution of the current research are now discussed.

How and why people form social support connections at times of stress and what makes for strong bonds has been the subject of much research (Thoits, 1986). Previous research into successful volunteer mentoring interventions for carers of people with dementia has tended to focus on Homophily Theory as a way of explaining how 'similar others' form bonds (Pillemer & Suitor, 2002; Sabir et al, 2003). This has been explored and expanded upon in this thesis, with Homophily Theory being shown to be useful as part of a theoretical framework in explaining the formation of mutually supportive relationships. This framework consisted of Homophily Theory and SET to highlight the process by which carers and volunteers develop strong and trusting bonds leading to reciprocity (Figure 10). Social exchange also suggests a reason for volunteers engaging with these services as a way of benefitting themselves by helping others. The survey (Chapter Five) showed managers and volunteer coordinators reported matching carers and volunteers on structural (demographic) features such as age, gender and common interests was important. This can be explained by structural homophily by helping people to form connections with each other based on similar social attributes. However, experiential similarity was not viewed as important, which this research argues is key to the development of trusting relationships. Thus, it is argued that without experiential similarity carers and volunteers may not develop the level of trust necessary to engage in social exchange and form mutually beneficial relationships.

The importance of experiential similarity has implications for befriending services. Whilst peer support services (by definition) would be more likely to have the assistance of former carers as volunteers, for befriending services this would generally not be the case. Given the importance of experiential similarity, it could be argued that peer support services are the preferred types of support for carers of people with dementia. It could also be argued that if this research had focused specially on peer support, stronger inferences could be drawn as to the impact of the services. However, at the stage of developing the research questions and aims, too little was known about the differences of these services and how they may impact on carers of people with dementia. Since finishing the systematic review (Chapter Four), further research has been published indicating carers of people with dementia value peer support and the experiential similarity of the volunteers (Greenwood et al. 2013).

The methodological approach taken in this mixed methods research was one of pragmatism (Mertens, 2005). Previous research into social support for carers of people with dementia has typically focused on either quantitative (e.g. Charlesworth et al. 2008) or qualitative deigns (e.g. Stewart et al. 2006). By using a sequential explanatory design (Creswell & Plano Clark, 2011), it was possible to explore the impact of volunteer mentoring on carers from multiple methodological perspectives in a single research study.

8.11.1 Directions for future research

Future research should investigate carers' and volunteers' relationships over time to find out which aspects of similarity are more likely to lead to longer lasting mentoring relationships. Understanding at which point in the caring journey volunteer mentoring might be most useful to carers is also worthy of exploration. For example, if carers are able to access this support (should they choose to) early on after the person they are caring for has been diagnosed with dementia, it may reduce the chance of carers reaching crisis. Further, understanding the impact on the person with dementia by their carers receiving a volunteer mentoring intervention is needed. Carers in the current research said they felt more able to cope with challenges, had improved mood and that this could potentially impact positively on the person they were caring for.

There is an established association between mental and physical health, with lower levels of social support in the elderly (Bowling, 1991). With the statistically significant improvements in perceived social support found in this research, future research should consider investigating the impact of volunteer mentoring on the physical health of carers of people with dementia.

8.11.1 Implications for policy and practice

English government policy relating to carers of people with dementia (and carers more generally) highlighted the implementation and development of peer support services, without there being an evidence base the intervention impacts positively on the carers currently using them. This research has shown that, whilst little impact was observed on quantitative measures of anxiety, depression and loneliness, qualitative evidence suggests carers benefit from accessing them. In particular, the release of negative emotions, gaining advice on ways of caring and subsequently feeling as though they can continue caring for longer. This has implications for keeping carers supported in the community without the need to access health and social care services, and also helping to keep people with dementia cared for in their own homes for longer.

Commissioners looking to implement support services for carers of people with dementia should consider the possibility of three sets of people both directly or indirectly, benefiting from the development and funding of volunteer mentoring interventions. For example: helping to keep current carers supported; helping former carers to engage in mutually beneficial relationships; and potentially strengthening the relationships between carers and the people they care for. This research has also highlighted the importance of varied and flexible support for carers, as no one model of social support is suitable for all. For example, some carers talked about how they perceived it to be difficult to discuss sensitive or taboo topics within a group setting. This is something which was easier to do in a one-to-one situation with a former carer.

In developing and implementing new volunteer mentoring services for carers of people with dementia, commissioners and service managers should consider that it is likely to work best as part of a much larger support system for carers. More attention needs to be given to the potential impact on volunteers. Whilst the experiential similarity of former carers was an important aspect to the formation of mutually beneficial relationships, carers talked about how it could potentially bring back painful memories for volunteers and be emotionally challenging for them. To this end, effective and continued support and supervision for volunteers, where they can discuss any difficulties they may be having, should be considered by services not currently offering this.

Whilst these practice and service implications are important to draw out of this thesis, the previously mentioned limitations and lack of generalisability to other nations of the UK other than England should be noted by commissioners and service managers. Further research is necessary to assess whether these finding are replicable in other locations and if other models of volunteer mentoring support are more appropriate for different populations.

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Appendices

Appendix 1: Published version of the systematic review

Review

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The Impact of Volunteer Mentoring Schemes on Carers of People With Dementia and Volunteer Mentors: A Systematic Review

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Abstract

This systematic review aims to examine the differences and similarities between the various types of volunteer mentoring (befriending, mentoring and peer support) and to identify the benefits for carers and volunteers. Literature searching was performed using 8 electronic databases, gray literature, and reference list searching of relevant systematic reviews. Searches were carried out in January 2013. Four studies fitted the inclusion criteria, with 3 investigating peer support and 1 befriending for carers. Quantitative findings highlighted a weak but statistically significant ($P = .04$) reduction in depression after 6 months of befriending. Qualitative findings highlighted the value carers placed on the volunteer mentors' experiential similarity. Matching was not essential for the development of successful volunteer mentoring relationships. In conclusion, the lack of need for matching and the importance of experiential similarity deserve further investigation. However, this review highlights a lack of demonstrated efficacy of volunteer mentoring for carers of people with dementia.

Keywords

carer, caregiving, dementia, befriending, peer support, volunteer

Background

Carers

It is estimated that worldwide there are currently 35.6 million people living with dementia, rising to potentially 100 million by 2050.[1] The number of informal, unpaid carers is increasing at a similar rate.[2] Carers of people with dementia are reported to be under more mental and physical strain than carers of other older people.[3] This may be largely due to the extra stress the symptoms of dementia can cause, such as memory loss, communication difficulties, incontinence, decreased mobility, agitation, and aggressive behavior.[4] With this, they are more likely to experience loneliness, social exclusion, and physical and mental health issues.[5-7] This is of concern, as isolation and loneliness are key contributors to carer stress.[8]

Volunteering

There are many reasons for choosing to volunteer. For example, volunteering increases social integration, giving volunteers opportunities to interact with others, which in turn may have a positive impact on mental well-being.[9] Also, social integration, reductions in depression, and improvements in physical health have been highlighted as benefits of volunteering.[10,11] This is supported by Piliavin and Siegl[12] who demonstrated that volunteering is associated with psychological well-being, with those who were less well socially integrated benefitting the most. This finding could be explained by Prouteau and Wolff[13] who focused on understanding the relational motives for the reasons why people volunteer. They found that volunteers expressed a strong desire to make friends and meet people by increasing their social circle through volunteering.

Social Support Interventions

There are a variety of interventions aimed at reducing social isolation and increasing social inclusion for carers.[14-16] These interventions include a number variously known as befriending, mentoring, and peer support. Greenwood and Habibi[17(p10)] define mentoring as "*a mixture of emotional and social support provided by a non-judgemental outsider.*" Similarly, Dean and Goodlad[18(p5)] define befriending as "*A relationship between two or more individuals . . . the relationship is non-judgemental,*

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mutual, purposeful, and there is a commitment over time." However, a peer supporter has been described as " . . . *someone who has faced the same significant challenges as the support recipient,* (and) *serves as a mentor to that individual.*"[19(p140)] highlighting a key difference between peer support, befriending, and mentoring. However, for the purposes of this article, all these interventions will be referred to as volunteer mentoring. Although carers often report isolation and social exclusion, there is little evidence to suggest the types of social interventions that are effective at reducing this.[14] However, there is some evidence for improving well-being, for example, a recent meta-analysis by Mead et al[20] found one-to-one befriending had a modest effect on depression in various patient groups, including carers. However, it should be noted that Mead et al[20] also included studies where paid workers delivered the befriending intervention alongside volunteers. Further to this, peer support, another intervention based on social support, has been shown to have a positive impact on carer well-being.[21]

The Importance of This Review

Given the lack of demonstrable efficacy in general of interventions for carers of people with dementia[15,22] and the likelihood that the number of volunteer mentoring schemes will increase,[23] research for their use in this population is warranted. It is important to understand how these schemes operate and what impact, if any, they have on carers and volunteers. Improved understanding of their impact overall should help determine which types of volunteer mentoring (peer support, mentoring or befriending) have the greatest benefits and for whom.

Aims and Research Questions

The aims of this systematic review are to investigate and appraise the empirical evidence for the impact of different types of mentoring schemes on both carers of people with dementia and volunteers. It will identify the current level of knowledge and any gaps in the literature.

This review takes the evidence further than other reviews[20] by focusing specifically on 3 forms of volunteer mentoring (befriending, mentoring, and peer support) and highlighting the similarities and differences between them. Further, this review is not only limited to the impact on mental health of carers (eg, Mead et al[20]) but also incorporates the impact on social aspects of volunteer mentoring. To provide more focused answers, this review is also limited specifically to volunteers as opposed to professionals delivering a volunteer mentoring intervention for carers of people with dementia.

The specific questions are as follows:

1. What are the differences and similarities between the different types of mentoring schemes in how they operate? For example, frequency of sessions and length of contact.
2. What outcomes are investigated for carers and volunteers?
3. What is the evidence of the impact these interventions have on carers and volunteer mentors?
4. What is important for successful volunteer mentor and carer relationships?

Methods

To ensure transparency and completeness of the review, the preferred reporting items for systematic reviews and meta-analyses (PRISMA) checklist[24] was used.

Inclusion and Exclusion Criteria

Articles were included if the person being cared for had a diagnosis of dementia, the intervention was delivered by volunteers on a one-to-one basis, and the articles were written in English. Quantitative, qualitative, and mixed method studies were included. Studies were excluded if it was not possible to identify whether the main effects were due to volunteer mentoring; the interventions were not clearly identified as befriending, mentoring, or peer support; or less than 50% of the participants were carers of people with dementia. Review articles, conference papers, and dissertations were also excluded.

Study Identification

An online database search was conducted using Ovid Medline (1946 to January week 2, 2013), Embase (1980 to January week 2, 2013), PsychINFO (1967 to January week 2, 2013), Social Policy and Practice (1981 to January week 2, 2013), Cinahl Plus (1937 to January week 2, 2013), Allied and Complimentary Medicine (1985 to January week 2, 2013), The Social Sciences Citation Index (1970 to January week 2, 2013), and Scopus (1960 to January week 2, 2013). Searches were limited to the English language.

Search strategies consisted of both Medical Subject Heading (MeSH) terms and key words. The search strategy used for Medline was as follows: (the MeSH terms used are reported in italics), (exp *caregivers* OR caregiver* OR care giver* OR carer*) AND (*social support* OR *voluntary workers* OR *voluntary programs* OR *mentors* OR *telephone* OR *interne*t OR befriend* OR peer support* OR mentor* OR voluntary OR volunteer* OR social support* OR psychosocial intervention OR online OR internet OR telephone) AND (*depression* OR *anxiety* OR *mental health* OR *mental disorders* OR *social isolation* OR *social support* OR *self concept* OR *loneliness* OR *stress, psychological* OR *quality of life* OR depression OR anxiety OR mental health OR social isolation OR social support OR social inclusion OR social exclusion OR self worth OR selfworth OR self esteem OR selfesteem OR burden* OR hopeless* OR quality of life OR stress*) AND (*dementia* OR *dementia, vascular* OR *Alzheimer disease* OR dement* OR Alzheimer* OR vascular dementia).

Reference list searching of relevant identified systematic reviews and of all included studies was undertaken. Gray

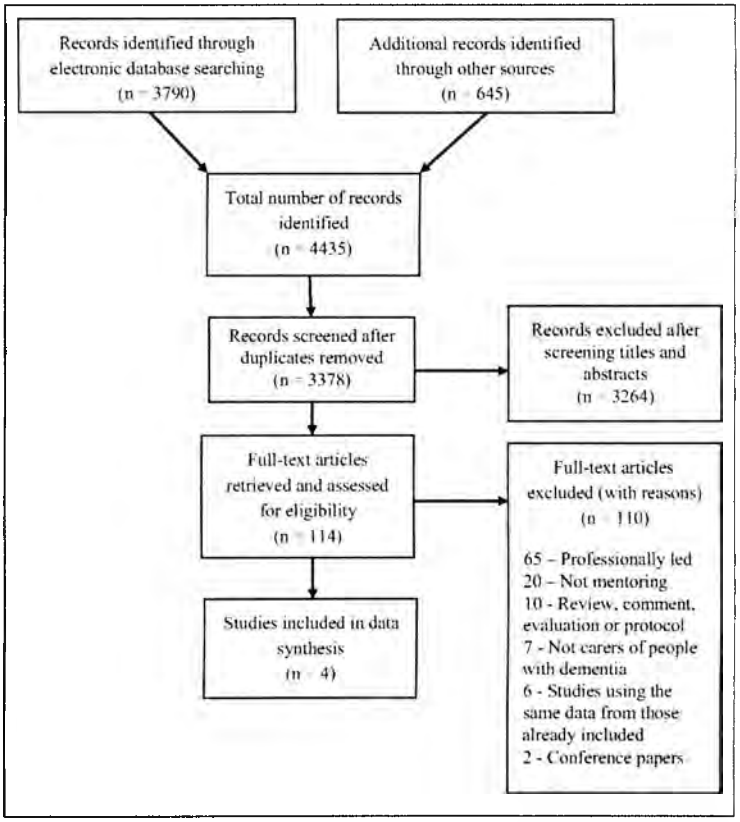

Figure 1. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram[24] showing the process of including and excluding retrieved articles.

literature searches were performed using the Alzheimer's Society Web site, the Mentoring and Befriending Foundation Web site, the AgeUK Web site, the Joseph Rowntree Foundation Web site, Open Grey, the UK Institutional Repository Search and Zetoc. Further, contact was made with 6 experts in the field of research to see whether they could provide any further studies not identified as part of the literature searches.

Quality Assessment

Quality assessment of studies possible for inclusion in the review was undertaken using the QualSyst review tool.[25] This tool was selected because it permits scoring for both qualitative and quantitative studies. Quality scoring was conducted independently by 2 authors (R.S. and N.G.). The few differences in ratings were discussed and consensus was achieved. Quality assessment was used to interrogate the studies, but studies were not excluded based on quality scores.

Data Extraction and Management

Articles were separated into qualitative, quantitative, and mixed methods studies. Standardized data extraction forms were developed for all 3 types of study. Data extraction for quantitative studies included author details, year of publication and publication type, participant demographic details, sample size, interventions investigated, outcomes measured, results of intervention (on both carers and volunteers), and key findings. Data extracted for qualitative and mixed method studies were similar to quantitative studies, along with themes being identified.

Results

Electronic Searches

A flow diagram detailing the search results can be seen in Figure 1. Searches were performed in January 2013. A search of Medline revealed 834 results, Embase 1005 results, PsychINFO 657 results, Social Policy and Practice 178 results, Cinahl Plus 380 results, AMED 31 results, Social Sciences Citation Index 652 results, and Scopus 53 results. In total, 3790 titles and abstracts were identified. After 1057 duplicates were removed, the reviewers independently examined the remaining 2733 results and separately compiled a list of references to be examined. From this, 80 full-text articles were then retrieved for closer inspection, and after discussion between reviewers, 4 articles were subsequently included into the review from electronic searching.[26-29] Reasons for article exclusion are interventions being professionally led, they were not befriending, mentoring, or peer supporting, and they were not for carers of people with dementia. A full breakdown of reasons for article exclusion is available in Figure 1.

Reference List Searching Retrieved Reviews

A total of 16 literature reviews were retrieved from the electronic database searches and their reference lists hand searched (from this, 51 references were extracted and scrutinized). After the exclusion of repeats, 21 full-text articles were retrieved. None were eligible for inclusion.

Gray Literature Searching

Gray literature searches produced a total of 572 results. Of the 572 results reviewed, 7 full-text documents were sourced and checked for inclusion. Five were scrutinized but excluded for not meeting the inclusion criteria, the final 2 studies were excluded after collaboration between the reviewers.

Contact With Experts in the Field of Research

In all, 6 authors, including the 4 first authors from the included studies, were contacted to ask whether they were aware of any unpublished research relating to mentoring of carers of people with dementia. One author responded and no further studies were identified.

Reference List Searching of Included Studies

From the reference lists of the 4 included studies, 22 references were highlighted for further investigation.[26-29] Of these, 16 were repeats from either the earlier electronic searches or the reference searching of relevant reviews. Full-text articles of the remaining 6 were retrieved and examined for possible inclusion. All 6 were excluded after comparison with the inclusion criteria.

Included Studies

After discussion between the reviewers, 4 articles were included in the final data synthesis. For ease of reporting, the volunteer mentoring schemes were broken down by type (peer support or befriending).

Characteristics of Included Studies. Of the included studies, 2 studies came from the United States,[27,28] 1 from Canada,[29] and 1 from the United Kingdom.[26] Two studies were randomized controlled trials,[26,27] 1 observational,[28] and the fourth was qualitative and used content analysis.[29] All but 1 study,[29] which also included carers of stroke survivors, focused exclusively on carers of people with dementia.

A variety of different outcomes were measured. Two studies focused on mental health,[26,27] 1 on carer and volunteer mentor similarity and continuation of visits,[28] and the final study investigated the types of support offered by peer volunteers and carer satisfaction with the service received.[29] Two studies focused on face-to-face peer support from the same trial,[27,28] 1 on one-to-one telephone peer support,[29] and 1 on one-to-one, face-to-face befriending.[26] Full details of the characteristics and methods of the included studies are available in Tables 1 and 2.

Methodological Quality of Included Studies. The result and overall quality scores of included studies can be seen in Table 3. The maximum possible score is 100. The average quality score across all 4 studies was 75. Charlesworth et al[26] received a score of 100, Pillemer and Suitor[27] scored 71, while both Sabir et al[28] and Stewart et al[29] scored 65. The quantitative studies scored more highly than the qualitative study, averaging a score of 79 compared to 65. The main issues with the quantitative studies tended to be the omission of estimates of variance[27,28] and blinding procedures.[27] The main quality issues with Stewart et al's[29] study were lack of verification procedures and omission of an account of reflexivity. Of the 4 studies, 3 described attrition,[26,27,29] but only Charlesworth et al[26] and Stewart et al[29] documented reasons for participant withdrawal. Attrition ranged 19%,[26] 22%[27] and 30%.[29] The lack of attrition data for Sabir et al[28] means it is not known whether participant withdrawals were excluded from the analysis, increasing the chances of bias.

Peer Support

Two studies investigated face-to-face peer support, reporting different findings from the same trial (Pillemer and Suitor[27] and Sabir et al[28]). The volunteers who took part in the trial needed to have prior caring experience. One study was quantitative with a qualitative element.[27] These primarily quantitative face-to-face peer support studies looked at different outcomes, and neither found statistically significant effects. Pillemer and Suitor[27] found no positive improvements in either depression or carer self-esteem. However, after secondary analysis, peer support was found to have a modest buffering effect on depressive symptoms for carers experiencing the most stressful situations. The qualitative data described by Pillemer and Suitor[27] highlighted that carers expressed experiential similarity as one of the most positive features of the intervention. This was also found by Sabir et al[28] who showed that carers were more likely to have successful peer support relationships and to continue meeting after the intervention ended, if they were similar on the shared experience of caring. Extensive matching criteria were not found to influence a successful peer support relationship.

Table 1. Characteristics of Included Studies.

Authors (Year Published) and Location [Country]	Aims	Sample Size	No. of Participants	No. of Controls	Carers' Mean Age in Years (Standard Deviation)	Mentors' Mean Age in Years (Standard Deviation)	Participant Gender Ratios (M:F, %)	Participant Ethnicity
Charlesworth et al (2008)[26] [UK]	To determine whether access to a befriender facilitator is effective compared with usual care	236	116	120	68 (11.4)	Not reported	36:64	99% of Participants were white
Pillemer and Suitor (2002)[27] [US]	To test whether adding peer support to carers' social network produces positive outcomes	147 (115 completers)	54	61	58 (Not reported)	Not reported	29:71	Not reported
Sabir et al (2003)[28] [US]	To identify predictors of successful carer and peer relationships	114 (57 matched carer and peer supporter pairs)	114	Not reported	62 (Not reported)	62 (Not reported)	25:75	Not reported
Stewart et al (2006)[29] [Canada]	Understanding the impact of telephone peer support for carers	66 (47 were carers of people with dementia)	66	N/A	60 (13.88)	64 (7.46)	34:66	Not reported

Abbreviations: F, female; M, male; N/A, not available.

Table 2. Methods of Included Studies.

Authors (Year Published)	Interventions Investigated	Participants Recruited From	Study Design	Study Period, Weeks	Session Length, Hours	Inclusion Criteria	Exclusion Criteria	Outcomes Measured (Data Collection Methods and Scales)
Charlesworth et al (2008)[26]	Befriending	Norfolk and Suffolk (UK) through mail outs from GP surgeries, leaflets sent to relevant organizations, press articles, and presentations	Randomized controlled trial with economic evaluation	104	1	Carers aged >18, caring for a person with dementia. At least 20 hours a week spent on care-related tasks	Carers with cognitive impairment or terminal illness. Carers of people in permanent residential accommodation	Anxiety and depression (HADS), loneliness (2-item measure), positive and negative affectivity (PANAS), relationship quality (MCBS), coping (COPE), social support (PANT), life events (LTE), health-related quality of life (EQ5-D), resource use (semi-structured interviews), perceived social support (MSPSS)
Pillemer and Suitor (2002)[27]	Peer support	State University of New York Health Science Centre	Mixed methods. Randomized controlled trial with a qualitative aspect	8	1-2	Person being cared for had to have a diagnosis of Alzheimer's disease	PWD could not reside in a nursing home at the preintervention interview stage	Depression (CES-D), Self-esteem (RSES), satisfaction with the service (participant interviews)
Sabir et al (2003)[28]	Peer support	State University of New York Health Science Centre	Observational study	8	1-2	PWD had to have a diagnosis of Alzheimer's disease	PWD could not reside in a nursing home at the preintervention interview stage	Number of volunteer visits, continuation of visits postintervention, and quality of carer/peer supporter match
Stewart et al (2006)[29]	Telephone peer support	Contact with relevant agencies, posters, presentations to groups, newspaper advertisements and mail outs to relevant organizations and services	Qualitative	20	15-60 minutes	Carers of a people with dementia or people with stroke	People being cared for who were under the age of 50	Types of support provided by peer supporters, support processes, perceived intervention impacts, and satisfaction with the intervention

Abbreviations: CES-D, the Centre for Epidemiological Studies Depression Scale; COPE, Coping Orientation for Problem Experience, EQ5-D, EuroQol 5 Dimensions; GP, General Practitioner; HADS, Hospital and Anxiety Depression Scale; LTE, List of Threatening Experiences; MCBS, Mutual Communal Behaviours Scale; MSPSS, Multidimensional Scale of Perceived Social Support; PANAS, Positive and Negative Affect Schedule; PANT, Practitioner Assessment of Network Type; PWD, person with dementia; RSES, Rosenberg Self-Esteem Scale.

Table 3. Results of Included Studies.

Authors (Year Published)	Results of Interventions on Carers	Results of Interventions on Volunteers	Themes Identified (Qualitative and Mixed Methods Studies)	Measure Used to Rate Participant Withdrawals	Number of Participants Who Withdrew, n (%)	Conclusions	Quality Score
Charlesworth et al (2008)[26]	No statistically significant effect across the outcomes measured	Not reported	N/A	Reasons for participant withdrawal included the death of the carer and carer ill health	46 (19%)	Befriending for carers of people with dementia is not an effective intervention	100
Pillemer and Suitor (2002)[27]	No positive effects were found for either depression or self-esteem	Not reported	Experiential similarity. Sharing experiences with someone who has been through something similar was seen as highly important to carers	Not reported	32 (22%)	Peer support for carers of people with dementia is not an effective intervention	71
Sabir et al (2003)[28]	No statistically significant difference found for carer and peer supporter similarity and number of visits made	Not reported	N/A	Not reported	Not reported	Extensive matching criteria are not essential for a successful peer support intervention for carers of people with Alzheimer's disease	65
Stewart et al (2006)[29]	Increased satisfaction with support, coping skills, caregiving competence, confidence, and decreased burden and loneliness	Not reported	Carers knowing that they are not alone. Having someone there who understands what they are going through. Experiential similarity is seen as important	Reasons for participant withdrawal included ill health of the person cared for and carer constraints	20 (30%)	Use of telephone peer support provides an accessible, cost-effective and efficient means of communication to carers	65

Abbreviation: N/A, not available.

Despite both studies showing experiential similarity as potentially having a positive impact on peer support relationships, the overall finding is that peer support for carers of people with dementia is not an effective intervention.

Although the quantitative studies mostly reported no impact of face-to-face peer support, the qualitative study by Stewart et al[29] suggested telephone peer support was beneficial. This study focused on telephone peer support for carers of people with dementia and stroke survivors and showed an increase in coping skills and caregiving competence and a decrease in loneliness and reliance on other forms of social support. Carers also reported receiving emotional support from telephone peer supporters. This was seen as vital as carers reported losing support from family and friends following diagnosis of the person with dementia. Most of the positive impacts were perceived to come from peer supporters' experiential knowledge of the carers' situation. Experiential similarity was seen as highly important. Overall, it was concluded that telephone peer support provides accessible, cost-effective, and beneficial support for carers.

Befriending

Of the 4 included studies, 1 study[26] investigated face-to-face befriending. Carers were offered access to a befriending facilitator, with approximately half the carers taking up the service. Volunteer befrienders did not need prior caring experience. Befriending lasted between 6 and 24 months. Overall, there were no statistically significant benefits of the intervention over the control group for either psychological well-being or cost-effectiveness. No improvement was found for carers in the intention-to-treat population, as measured by the Hospital and Anxiety Depression Scale ($P = .71$). However, carers receiving the befriending intervention for at least 6 months reported a statistically significant improvement in depression scores at 15 months ($P = .04$). In addition, across the secondary outcomes, there were no statistically significant positive effects for the intervention over the control and there was no evidence for the cost-effectiveness for befriending. It was concluded that access to a befriender facilitator was not an effective intervention. However, it was suggested that future research into befriending schemes is warranted due to the trend for a statistically significant reduction in depression after 6 months.

Discussion

This review highlights both the paucity of studies and the inconsistent findings in the available research for the effectiveness of volunteer mentoring schemes for both carers of people with dementia and volunteers. This is a concern, as it is likely these schemes will increase in number.[23] It also highlighted the differences in qualitative and quantitative findings. Although the quantitative results largely showed no impact of volunteer mentoring, qualitative findings suggested carers value the support the schemes can give and the experiential similarity of the volunteers. Overall, the findings of this review are in line with previous research, which highlights a lack of demonstrated efficacy for interventions for carers of people with dementia.[22] However, the results suggesting the importance of experiential similarity for carers have also been reported elsewhere,[30,31] making this an important area for further exploration.

Differences in How the Schemes Operate

There appears to be similarities between befriending[26] and peer support[27-29] in terms of how the schemes operate. Typically, interventions last for 1 hour and take place once a week, although telephone peer support may allow carers and volunteers more flexibility over when and how long mentoring sessions last.[29] The most notable difference between the schemes is that peer support requires volunteers to have prior caring experience, whereas befriending does not. However, as few studies were identified, caution is needed when comparing these types of mentoring schemes.

Impact on Carers and Volunteers

The studies investigated numerous outcomes including depression, anxiety, perceived social support, self-esteem, number of volunteer visits, and satisfaction. Quantitative studies of befriending and peer support were shown to be ineffective in reducing mental health issues and loneliness in carers.[26,27] However, the qualitative study[29] showed that carers reported reduced burden and loneliness, both of which have been correlated with levels of stress and mental health issues.[5,8] Further research could help clarify the reasons for this finding. It is possible that the study by Stewart et al,[29] which focused on telephone peer support, offered a more flexible and effective means of communication and support with carers, leading to better outcomes. However, the differences in research design could be an issue, as research has highlighted participants reporting more positively or negatively depending on how the data are collected.[32]

The small but significant difference shown in depression scores at 15 months for carers who received befriending for at least 6 months[26] could indicate that the benefits of befriending might not be immediate, and therefore more longitudinal studies are needed. Also, it is possible that the use of validated outcome scales[26,27] may not be focusing on the aspects of volunteer mentoring which are most important to carers. This could, in part, explain the differences found between the quantitative and the qualitative investigations.

Although there have been a number of benefits attributed to volunteering,[12] none of the studies included here investigated the impact of volunteering on befrienders, mentors, or peer supporters, making it an important area for future exploratory investigations.

Developing Successful Carer and Volunteer Mentor Relationships

The development of successful mentoring relationships was also thought to be associated with the experiential similarity of volunteer mentors. The importance of this was reported by

3 of the included studies.[27-29] In particular, Sabir et al[28] reported that it was not essential to implement extensive matching criteria prior to pairing carers and mentors, but it was important that mentors had previous experience of caring. In fact, it was shown that dissimilar pairs had more contact than pairs matched across a wide range of demographics. In this review, the finding of the importance of experiential similarity is consistent with the findings from previous research[30,31] and highlights that extensive matching criteria are not needed. However, more research is needed to explore what it is about experiential similarity that makes it important in mentoring relationships.

Limitations of Included Studies and Their Possible Impact on Findings

The level of participant withdrawal from both the research and the interventions is of concern. Stewart et al[29] reported 30% withdrew over the course of the 20-week study period, considerably more than the studies by Charlesworth et al[26] (19%) or Pillemer and Suitor[27] (22%). The 2 studies that did report reasons for participant withdrawal from the research highlighted ill health of the carers as an overriding factor. The high level of withdrawal from the Stewart et al's[29] study needs to be taken into consideration when examining the results. Attrition bias could have led to only the healthiest carers or those coping best completing the study. Also, although the authors noted that dissatisfaction with the peer support was not cited as a reason, it is possible that claiming ill health rather than dissatisfaction might have been seen as a more acceptable explanation for carers to give. Improved understanding of the processes of mentoring from the carers' and volunteers' perspectives may help identify difficulties they may experience during mentoring, which may at least be partially responsible for some of the withdrawals.

Second, the low uptake of the schemes limits the generalizability of the results. Charlesworth et al[26] reported low uptake of befriending by carers despite having access to a befriender facilitator. Those who did take part for 6 months or more showed some improvements in depression scores over the control group. This low uptake needs further investigation to understand why it occurs and whether it is a reflection of the general reluctance carers have in accepting support.[33]

Strengths and Limitations of the Review

The main strength of this review is the inclusive study design, the large body of literature that was examined from a number of different sources, and its specific focus. Earlier reviews have been more generally focusing on the impact of support schemes for carers of people with dementia.[6,20]

A main limitation is the dearth of published and unpublished research, which resulted in only 4 studies being included. Although this highlights a lack of research in this field, it influences the power of the conclusions that can be drawn from the results. A second limitation is that only articles published in English were included, which could have led to potentially important studies being missed.

Future Directions

Given the lack of clarity in terms of differences and similarities between the different types of volunteer mentoring schemes, further research is required. This is potentially an important area of future research to help understand the models of mentoring that work best, possibly leading to more effective schemes being offered. This could include comparisons of volunteer mentoring with similar interventions that are professionally led. No studies investigated the impact of volunteering on the volunteer mentors. Given the evidence that there could be a positive impact on volunteers' well-being,[9,11,12] future research is needed to identify the impact, if any, on volunteers providing volunteer mentoring. Furthermore, the potential impact on the person with dementia is worthy of investigation.

Conclusions

There is little quantitative evidence that volunteer mentoring improves outcomes for carers of people with dementia. However, qualitative evidence shows carers value volunteer mentoring and opportunities to talk about their experiences. The lack of need for matching and the importance of experiential similarity are significant issues deserving further investigation. However, overall the findings of this review are in line with previous research that highlights a lack of demonstrated efficacy for interventions for carers of people with dementia.

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Appendix 2: Systematic review protocol

The Impact of Volunteer Mentoring Schemes on Carers of People with Dementia and Volunteer Mentors

A Protocol for a Systematic Review

The following is a protocol for a systematic review investigating the impact of volunteer mentoring schemes on carers of people with dementia and on volunteers. For consistency the term 'mentoring' will be used when commenting on befriending, mentoring, and peer support collectively.

Background

As of 2005, there were approximately 24.3 million people living with dementia worldwide, with 4.6 million new cases every year (Ferri et al. 2005). In the UK, it was estimated that as of 2007 there were 700,000 people living with dementia, rising to over 1 million by 2025 with an annual cost to the UK of £17.05 billion (Knapp et al. 2007). There are approximately 6 million carers in the UK which could increase by a quarter by 2014-15 (Lewis et al. 2009), with carers of people with dementia saving the UK economy an estimated £6 billion per year (Luengo-Fernandez et al. 2010). With this in mind, it is important to find ways of supporting carers of people with dementia effectively for the long-term.

Description of the challenges carers face

For many carers their role has a negative impact on their mental well-being, physical health, relationships, finances and social activities (Carers UK, 2004). This is also highlighted by Carers Scotland (2011) which showed that as much as 86% of carers reported they suffer from depression, anxiety or stress; 71% reported back or shoulder pain; and 54% reported feeling isolated and that they could no longer take part in social activities or meet with friends and family. In particular, carers of people with dementia fare worse than carers of people with other long-term illness in terms of mental distress and poor physical health (Pinquart & Sorensen, 2003). This is supported by Mahoney et al. (2005) who found that carers of people with dementia suffer from high rates of anxiety and depression, with females more likely than males to be suffering from mental distress. The importance of tackling loneliness in carers of people with dementia was highlighted by Beeson (2003). In this study carers of people with Alzheimer's disease reported greater loneliness than non-carers, which was correlated with increased feeling of depression.

There is evidence to suggest the negative impacts of caring may affect the person being cared for. In a recent review of the literature, Etters et al. (2008) set out to identify factors influencing dementia-related carer burden. It was found that care giving was associated with negative impacts on carers' health and that people with dementia face earlier placement in care homes as a result. The authors suggested that diverse multi-component interventions which can reduce carer burden will improve the quality of life of carers.

Given that the number of carers is set grow as the number of people living with dementia increase (Knapp et al. 2007), it is important to find ways of helping support carers and to reduce the level of mental distress and isolation they can often feel (Carers UK, 2004).

Why do people volunteer?

A number of explanations for why people volunteer have been proposed. For example, it has been hypothesised that a person who volunteers is becoming socially integrated and giving themselves opportunities to interact with other people, which in turn could impact positively on their mental well-being (Choi & Bohman, 2007). There is also Activity Theory (Lemon et al. 1972), which postulates that there is a positive relationship between staying active in later life and life satisfaction. It could be that volunteering gives back a role to people they have lost and helps people to form relationships and engage in social activities.

In a review by Volunteering England (Casiday et al. 2008) it was shown that volunteering can deliver health benefits to both volunteers and to service users. They found that volunteering led to an improvement in self-rated health, mental health, life satisfaction, coping ability, social interaction and healthy behaviours. The improvement was similar for the people the volunteers were supporting, with improvements in self-esteem, mental health, physical health and relationships. This is supported by Harris and Thoresen (2005) who found that volunteering is associated with reduced mortality when compared with non-volunteers in people over the age of 70. This would indicate that volunteering has an overall positive effect on the volunteers and can give them a sense of purpose and role in life. However, a study by Ferrari et al. (2007) found that caregivers were less satisfied with volunteers than with paid employees. It was suggested that the volunteers were not as well trained as the paid employees were in being able to handle carer burdens.

Description of the interventions and how they might work

One possible way of decreasing levels of loneliness and increasing social inclusion in carers and volunteers is by engaging in mentoring schemes (Cattan et al. 2011). This study found that befriending schemes in particular provide a low cost means for isolated people to become more socially included and give them an increase in self-worth. Casiday et al. (2008) showed that volunteering is beneficial for both volunteers and for carers in terms of physical health, mental health and social inclusion. It has been suggested that people are more likely to engage in, and maintain supportive relationships with those who have a similar background and have gone through similar experiences, with Homophily Theory in part explaining this (Pillemer & Suitor, 2002). How well this relates to carers of people with dementia who take part in mentoring schemes will be one of the aims of this review. Below are descriptions and definition of the interventions which will be the focus of this review. Although buddying may have been included, it tends to relate more to educational or work settings and very seldom applies carers, so for this reason it will be excluded.

Befriending

Dean and Goodlad (1998, p 5) define befriending as "A relationship between two or more individuals which is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit. Ideally the relationship is non-judgemental, mutual, purposeful, and there is a commitment over time". Also McGowan et al. (2009, p 624) suggested that befriending may be a route to a better quality of life for many people "….a befriending relationship may be the beginning of a route back to gaining the increased confidence and self-esteem necessary to enable the individual to recreate and develop their own unique social network, improve their psychological well-being and enrich their quality of life".

Mentoring

Fowler and O'Gorman (2005) described a mentor as "...someone who has advanced experience and knowledge and who is committed to assisting, guiding and providing support in your career, personal and professional development". Whilst their study was primarily concerned with mentoring in the work place, it does highlight how a mentor in general will be a more experienced person imparting their knowledge onto another, less experienced person. A more vague definition describes mentoring as "...advice and support given to those who need it by influential people who wish to be helpful" (Haring, 1999). These definitions indicate that mentoring is often provided to those who are lacking information and who may need guidance in order to make the most out of a situation.

Peer support/peer mentoring

A peer has been described as "…someone who has faced the same significant challenges as the support recipient, (and) serves as a mentor to that individual" (Sherman et al. 2004). Also peer mentoring has been described as unique, "…this relationship provides unique support, something not duplicated by spouses, counsellors, or other supportive relationships" (Eckenroad & Hamilton, 2000, cited in Veith et al. 2006). Whilst there could be seen as overlap between mentoring and peer mentoring/support, it should be stated that a mentor does not necessarily have the same previous experience as that of the mentee, whereas as that is seen as imperative in peer mentoring relationships.

The importance of this review

The evidence for the effectiveness of befriending, mentoring and peer support schemes for carers is conflicting, with some studies finding positive outcomes (Mead et al. 2010), and others showing a lack of positive impact (Charlesworth et al. 2008). The systematic review will aim to identify the outcomes of schemes that support carers of people with dementia, enabling conclusions to be drawn on effectiveness and identify future areas of possible research.

Specific aims and research questions

The aims of this systematic review are to investigate and appraise the empirical evidence as to what impact different types of mentoring and befriending schemes have on both carers of people with dementia and on volunteers. It also aims to highlight the differences between the schemes in how they operate; especially the different roles adopted by mentors, from previous investigative research. This will help identify the current level of knowledge and gaps in the literature regarding this subject area.

The specific research questions are as follows:

1) What are the differences and similarities between the different mentoring and befriending schemes in how they operate? For example, frequency and length of contact.

2) What are the differences between the schemes in terms of the types of relationships volunteers and carers form? For example, friendships or professional relationships.

3) What outcomes are investigated?

4) What is the evidence of the impact these interventions have on carers, people with dementia and volunteers?

5) What challenges do volunteers face, for example in forming, maintaining and ending mentoring relationships?

6) Is the 'matching' of volunteers and carers considered as important by the provider organisation, volunteer or carer, and does it use have an impact?

The specific question formation was addressed using the Patient, Intervention, Comparison and Outcome (PICO) process as documented by the CRD (2008):

Patients	Interventions	Comparisons	Outcomes
Carers of people with dementia and volunteers	Befriending, mentoring or peer support schemes	Usual care (if available) compared with the interventions	For example: impact on mental health, social isolation, self-esteem, quality of life and formation of relationships; for both carers and volunteers

Methods

Search strategy

The search strategy will include searching electronic databases, reference searching of relevant systematic reviews, reference searching of included articles, grey literature searching and experts in the field of research will also be contacted. Two reviewers (RS and NG) will independently review the titles and abstracts of studies found in the search, with possibly relevant full-text articles being retrieved for further investigation. All full-text articles considered for inclusion in the systematic review will be recorded with explanations for exclusion (if applicable) being presented in a table with the article reference.

Electronic search strategy

The following electronic databases will be searched without date restrictions:

- MEDLINE(R) (OvidSP) - 1946 to 2011 December week four
- Embase (OvidSP) - 1980 to 2012 January week one
- PsychINFO (OvidSP) - 1967 to 2012 January week one
- CINAHL plus (EBSCOhost) - 1937 to 2012 January week one
- The Allied and Complementary Medicine Database (AMED) (EBSCOhost) - 1985 to 2012 January week one
- Social Policy and Practice (OvisSP) - 1981 to 2012 January week one
- Social Sciences Citation Index (Web of Science) - 1970 to 2012 January week one
- Scopus - 1960 to 2012 January week one

See Appendix 2 for an example search strategy using MEDLINE (OvidSP). Similar search strategies will be designed dependent on the databases used (listed above). All key words and combinations will be the same throughout the database searching. All MeSH terms will also be searched as keywords.

The following will be used as MeSH subject headings (in italics) and key word search terms (with truncation where appropriate): '*exp caregiver*', 'carer*', 'care giver*', 'caregiver*', ‘*social support*’, ‘*voluntary workers*’, *voluntary programs*’, *mentors*’, *telephone*’, ‘*internet*’, ‘befriend*’, ‘peer support’, ‘mentor*’, ‘volunteer*’, ‘voluntary’, ‘voluntary worker’, ‘social support’, ‘psychosocial intervention*’, ‘internet’, ‘telephone’, ‘*depression*’, ‘*anxiety*’, ‘*mental health*’, ‘*social isolation*’, *social support*’, ‘*self concept*’, *loneliness*’, *stress, psychological*’, ‘*quality of life*’, ‘depression’, ‘anxiety’, ‘mental health’, ‘social isolation’, ‘social support’, ‘social inclusion’, ‘social exclusion’, ‘ self-worth’, ‘selfworth’, ‘self-esteem’, ‘selfesteem’, ‘burden*’, ‘hopeless*’, ‘quality of life’, ‘stress*’, ‘*dementia*’, ‘*dementia, vascular*’, ‘*Alzheimer's disease*’ ‘dement*’, ‘Alzheimer*’, ‘vascular dementia’.

Other sources to be searched

Named contact authors of included studies will be contacted if data are missing or unclear, for clarification of results and also to help identify any other research which may fit the inclusion criteria of the review. Experts in the field of research (approximately 5 have so far been identified through preliminary literature searching) will also be contacted to help identify unpublished research. All the full-text retrieved articles from automated searching will be imported into the reference management software RefWorks or if the full-text is not available online, hard copies will be sourced.

Grey literature

The Mentoring and Befriending Foundation which has a research and evaluation directory which includes published studies, research projects and evaluations on the impact of mentoring and befriending, will be searched for relevant studies. Other websites and organisations will be identified through internet searching in order to identify relevant unpublished literature. At the present time it is likely to include: The Alzheimer's Society, The Joseph Rowntree Foundation, Volunteering England and the King's Fund.

Selection criteria

Types of studies

A broad range of studies will be considered for inclusion. The systematic review will include studies using quantitative, qualitative and mixed methods approaches.

Inclusion criteria

- Studies which involve one to one or group volunteer support by befriending, mentoring or peer support to carers of people with dementia.

- Only studies where volunteers deliver the intervention will be included.
- Studies which involve face-to-face, telephone or internet support.
- Studies which identify the person being cared for as having dementia.
- The intervention may take place in any location, such as a carers' home, community based facilities or other appropriate setting.
- Both male and female carers will be included.
- Articles will be limited to English language.
- There will be no date restrictions.

Exclusion criteria

- Studies where it is not possible to identify if any main effects were due to mentoring.
- Studies which include carers of other types of illness or disability where carers of people with dementia make up less than 50% of the total number of participants.
- Studies which involve support not clearly identified as befriending, mentoring or peer support.
- Review articles will be excluded.
- Young carers (18 years or younger).

Quality assessment

The quality of potentially included studies will be assessed independently by two reviewers (RS and NG). Disagreements will be discussed and consensus achieved.

Quality assessment of studies possible for inclusion in the review will be undertaken using the QualSyst review tool (Kmet et al. 2004). Citing the lack of an empirically grounded quality assessment tool for the use with a variety of study designs, Kmet et al. (2004) developed both a qualitative and quantitative scoring system (QualSyst) by drawing upon existing published tools, to evaluate the quality of studies potentially eligible for inclusion in reviews. The QualSyst tool includes 14 questions for quantitative studies and 10 for qualitative studies and rates the answers to each question with a yes (2), partial (1) or no (0) outcome, with a maximum score of 28 for quantitative studies and 20 for qualitative studies. Mixed methods studies will be assessed for quality depending on data type using both scales. This quality assessment will then be used to interrogate the studies based on their methodological quality. Studies will not be excluded based on quality score.

Data extraction and management

Following quality assessment of the studies, they will be grouped into qualitative and quantitative studies. Data extraction forms have been developed for both quantitative and qualitative studies. The forms will contain both information from published articles and information gained from contact with study authors. The extracted data will be entered into standardised tables, one for quantitative studies and one for qualitative studies. Data extraction for quantitative studies will include author details, year of publication and publication type, participant demographics, sample size, intervention(s) investigated, outcomes measured, results of intervention impact (on both carers and volunteers) and key findings. Data extracted for qualitative studies will include those mentioned for quantitative studies along with themes extracted from the results. To test the forms are adequate and no unnecessary information is being extracted, the forms will be piloted on a small sample of papers prior to the review process starting.

Data synthesis

If there is sufficient data from quantitative studies then a meta-analysis will be performed. Data from qualitative studies will be content analysed to identify themes relating to the aims set out earlier in this protocol. Information from both quantitative and qualitative studies will be entered into a standardised table for comparison and identification of important results. The qualitative data and quantitative data will then be compared and contrasted in order to inform conclusions and directions for future research.

Presentation of findings

This systematic review protocol was developed using the guidelines from the Centre for Reviews and Dissemination (CRD), (2008). The systematic review will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), (Moher et al. 2009). This will also include a flow diagram showing the numbers of articles identified and subsequently included or excluded from the systematic review at each stage of the study selection process.

Time scale

The expected time scale for the completion of the systematic review is three months from the date of submitting the final version of this protocol. The literature searching and identification of relevant studies will be the first step completed, for which one month has been allowed.

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Appendix 3: Systematic review example search strategy (MEDLINE)

1	exp Caregivers/
2	Caregiver*
3	Care giver*
4	Carer*
5	1 or 2 or 3 or 4
6	Social Support/
7	Voluntary Workers/
8	Voluntary Programs/
9	Mentors/
10	Telephone/
11	Internet/
12	Befriend*
13	Peer support*
14	Mentor*
15	Voluntary
16	Volunteer*
17	Social support*
18	Psychosocial intervention
19	Online
20	Internet
21	Telephone
22	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23	5 and 22
24	Depression/
25	Anxiety/
26	Mental Health/
27	Mental Disorders/
28	Social Isolation/
29	Social Support/
30	Self Concept/
31	Loneliness/
32	Stress, Psychological/
33	"Quality of Life"/
34	Depression
35	Anxiety
36	Mental health
37	Social isolation
38	Social support
39	Social inclusion
40	Social exclusion
41	Self worth
42	Selfworth
43	Self esteem

44	Selfesteem
45	Burden*
46	Hopeless*
47	Quality of life
48	Stress$
49	24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
59	32 and 58
60	Dementia/
61	Dementia, Vascular/
62	Alzheimer Disease/
63	Dement*
64	Alzheimer*
65	Vascular dementia
66	60 or 61 or 62 or 63 or 64 or 65
67	58 and 66
68	limit 67 to (English language and humans)

Appendix 4: QualSyst quality assessment tool

Checklist for assessing the quality of quantitative studies (Kmet et al. 2004)

	Criteria	YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				▨
2	Study design evident and appropriate?				▨
3	Method of subject/comparison group selection <u>or</u> source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				▨
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				▨
14	Conclusions supported by the results?				▨

Manual for Quality Scoring of Quantitative Studies

Definitions and Instructions for Quality Assessment Scoring

How to calculate the summary score

Total sum = (number of "yes" * 2) + (number of "partials" * 1)

Total possible sum = 28 – (number of "N/A" * 2)

Summary score: total sum / total possible sum

Quality assessment

1. *Question or objective sufficiently described?*

Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) *all* of the following: purpose, subjects/target population, and the *specific* intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is *not* considered sufficiently described.
Partial: Vaguely/incompletely reported (e.g. "describe the effect of" or "examine the role of" or "assess opinion on many issues" or "explore the general attitudes"...); *or* some information has to be gathered from parts of the paper other than the introduction/background/objective section.
No: Question or objective is not reported, or is incomprehensible.
N/A: Should not be checked for this question.

2. *Design evident and appropriate to answer study question?*
(If the study question is not given, infer from the conclusions).
Yes: Design is easily identified and is appropriate to address the study question / objective.
Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; *or* design is easily identified but only partially addresses the study question.
No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); *or* design cannot be identified.
N/A: Should not be checked for this question.

3. *Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.*
Yes: Described and appropriate. Selection strategy *designed* (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., "cancer" -- ICD code or equivalent should be provided). *Studies of volunteers:* methods and setting of recruitment reported. *Surveys:* sampling frame/ strategy clearly described and appropriate.
Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as "volunteers" or "healthy volunteers". *Surveys:* target population mentioned but sampling strategy unclear.
No: No information provided. *Or* obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). *Or* presence of selection bias which likely seriously distorted the results (e.g., obvious selection on "exposure" in a case-control study).
N/A: Descriptive case series/reports.

4. *Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?*
Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If "healthy

volunteers" are used, age and sex must be reported (at minimum). *Decision analyses:* baseline estimates for input variables are clearly specified.
Partial: Poorly defined criteria (e.g. "hypertension", "healthy volunteers", "smoking"). *Or* incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). *Decision analyses:* incomplete reporting of baseline estimates for input variables.
No: No baseline / demographic information provided.
Decision analyses: baseline estimates of input variables not given.
N/A: Should not be checked for this question.

5. *If random allocation to treatment group was possible, is it described?*
Yes: True randomization done - requires a description of the method used (e.g., use of random numbers).
Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).
No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).
N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

6. *If interventional and blinding of investigators to intervention was possible, is it reported?*
Yes: Blinding reported.
Partial: Blinding reported but it is not clear who was blinded.
No: Blinding would have been possible (and was possibly done) but is not reported.
N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

7. *If interventional and blinding of subjects to intervention was possible, is it reported?*
Yes: Blinding reported.
Partial: Blinding reported but it is not clear who was blinded.
No: Blinding would have been possible (and was possibly done) but is not reported.
N/A: Observational studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports.

8. *Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias?*
Means of assessment reported?
Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, "objective" criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. *Surveys:* clear description (or reference to clear description) of questionnaire/interview content and response options. *Decision analyses:* sources of uncertainty are defined for all input variables.
Partial: Definition of measures leaves room for subjectivity, *or* not sure (i.e., not reported in detail, but probably acceptable). *Or* precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. *Or* instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). *Surveys:* description of questionnaire/interview content incomplete; response options unclear. *Decision analyses:* sources of uncertainty are defined only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. *Or* measures employ only ill-defined, subjective assessments, e.g. “anxiety” or “pain.” *Or* obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). *Surveys:* no description of questionnaire/interview content or response options. *Decision analyses:* sources of uncertainty are not defined for input variables.
N/A: Descriptive case series / reports.

9. *Sample size appropriate?*
Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > 1⁄2 effect size) and/or problems with multiple testing are evident. *Decision analyses:* size of modeled cohort / number of iterations specified and justified.
Partial: Insufficient data to assess sample size (e.g., sample seems “small” and there is no mention of power/sample size/effect size of interest and/or variance estimates aren’t provided). *Or* some statistically significant results with standard errors > 1⁄2 effect size (i.e., imprecise results). *Or* some statistically significant results in the absence of variance estimates. *Decision analyses:* incomplete description or justification of size of modeled cohort / number of iterations.
No: Obviously inadequate (e.g., statistically non-significant results and standard errors > 1⁄2 effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). *Decision analyses:* size of modeled cohort / number of iterations not specified.
N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. *Analysis described and appropriate?*
Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”/“Kaplan-Meier with log rank tests”, etc.) and appropriate.
Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. *Or* minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). *Or* multiple testing problems not addressed.
No: Analysis methods not described and cannot be determined. *Or* obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). *Or* a study with a descriptive goal/ objective is over-analyzed.
N/A: Descriptive case series / reports.

11. *Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/objective upon which the conclusions are based)?*
Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). *Decision analyses:* sensitivity analysis includes all variables in the model.
Partial: Undefined “+/-“ expressions. *Or* no specific data given, but insufficient power acknowledged as a problem. *Or* variance estimates not provided for all main results/outcomes. *Or* inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not

provide an estimate of the variance around the difference). *Decision analyses:* sensitivity analysis is limited, including only some variables in the model.
No: No information regarding uncertainty of the estimates. *Decision analyses:* No sensitivity analysis.
N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions

.

12. *Controlled for confounding?*
Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). *Or* appropriate control at the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc). *Decision analyses:* dependencies between variables fully accounted for (e.g., joint variables are considered).
Partial: Incomplete control of confounding. *Or* control of confounding reportedly done but not completely described. *Or* randomized study without report of comparability of baseline characteristics. *Or* confounding not considered, but not likely to have seriously distorted the results. *Decision analyses:* incomplete consideration of dependencies between variables.
No: Confounding not considered, and may have seriously distorted the results.
Decision analyses: dependencies between variables not considered.
N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. *Results reported in sufficient detail?*
Yes: Results include major outcomes and all mentioned secondary outcomes.
Partial: Quantitative results reported only for some outcomes. *Or* difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.
No: Quantitative results are reported for a subsample only, or "n" changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of "unknown" is not used where needed). *Or* results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as "more likely" without quantitative report of actual numbers).
N/A: Should not be checked for this question.

14. *Do the results support the conclusions?*
Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren't based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made *in addition to* rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., "suggesting," "possibly").
Partial: Some of the major conclusions are supported by the data, some are not.
Or speculative interpretations are not indicated as such. *Or* low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).
No: None or a very small minority of the major conclusions are supported by the data. *Or* negative findings clearly due to low power are reported as definitive evidence against the

alternate hypothesis. *Or* conclusions are missing. *Or* extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/ strategy).
N/A: Should not be checked for this question.

Checklist for assessing the quality of qualitative studies (Kmet et al. 2004)

	Criteria	**YES (2)**	**PARTIAL (1)**	**NO (0)**
1	Question / objective sufficiently described?			
2	Study design evident and appropriate?			
3	Context for the study clear?			
4	Connection to a theoretical framework / wider body of knowledge?			
5	Sampling strategy described, relevant and justified?			
6	Data collection methods clearly described and systematic?			
7	Data analysis clearly described and systematic?			
8	Use of verification procedure(s) to establish credibility?			
9	Conclusions supported by the results?			
10	Reflexivity of the account?			

Manual for Quality Scoring of Qualitative Studies

Definitions and Instructions for Quality Assessment Scoring
How to calculate the summary score
Total sum = (number of "yes" * 2) + (number of "partials" * 1)
Total possible sum = 20
Summary score: total sum / total possible sum
Quality assessment

1. *Question / objective clearly described?*
Yes: Research question or objective is clear by the end of the research process (if not at the outset).
Partial: Research question or objective is vaguely/incompletely reported.
No: Question or objective is not reported, or is incomprehensible.

2. *Design evident and appropriate to answer study question?*
(If the study question is not clearly identified, infer appropriateness from results/conclusions.)
Yes: Design is easily identified and is appropriate to address the study question.
Partial: Design is not clearly identified, but gross inappropriateness is not evident; *or* design is easily identified but a different method would have been more appropriate.

No: Design used is not appropriate to the study question (e.g. a causal hypothesis is tested using qualitative methods); *or* design cannot be identified.

3. *Context for the study is clear?*
Yes: The context/setting is adequately described, permitting the reader to relate the findings to other settings.
Partial: The context/setting is partially described.
No: The context/setting is not described.

4. *Connection to a theoretical framework / wider body of knowledge?*
Yes: The theoretical framework/wider body of knowledge informing the study and the methods used is sufficiently described and justified.
Partial: The theoretical framework/wider body of knowledge is not well described or justified; link to the study methods is not clear.
No: Theoretical framework/wider body of knowledge is not discussed.

5. *Sampling strategy described, relevant and justified?*
Yes: The sampling strategy is clearly described and justified. The sample includes the full range of relevant, possible cases/settings (i.e., more than simple convenience sampling), permitting conceptual (rather than statistical) generalizations.
Partial: The sampling strategy is not completely described, or is not fully justified. Or the sample does not include the full range of relevant, possible cases/settings (i.e., includes a convenience sample only).
No: Sampling strategy is not described.

6. D*ata collection methods clearly described and systematic?*
Yes: The data collection procedures are systematic, and clearly described, permitting an "audit trail" such that the procedures could be replicated.
Partial: Data collection procedures are not clearly described; difficult to determine if systematic or replicable.
No: Data collection procedures are not described.

7. *Data analysis clearly described, complete and systematic?*
Yes: Systematic analytic methods are clearly described, permitting an "audit trail" such that the procedures could be replicated. The iteration between the data and the explanations for the data (i.e., the theory) is clear – it is apparent how early, simple classifications evolved into more sophisticated coding structures which then evolved into clearly defined concepts/explanations for the data). Sufficient data is provided to allow the reader to judge whether the interpretation offered is adequately supported by the data.
Partial: Analytic methods are not fully described. *Or* the iterative link between data and theory is not clear.
No: The analytic methods are not described. *Or* it is not apparent that a link to theory informs the analysis.

8. *Use of verification procedure(s) to establish credibility of the study?*
Yes: One or more verification procedures were used to help establish credibility/ trustworthiness of the study (e.g., prolonged engagement in the field, triangulation, peer review or debriefing, negative case analysis, member checks, external audits/inter-rater reliability, "batch" analysis).
No: Verification procedure(s) not evident.

9. *Conclusions supported by the results?*
Yes: Sufficient original evidence supports the conclusions. A link to theory informs any claims of generalizability.
Partial: The conclusions are only partly supported by the data. *Or* claims of generalizability are not supported.
No: The conclusions are not supported by the data. *Or* conclusions are absent.

10. *Reflexivity of the account?*
Yes: The researcher explicitly assessed the likely impact of their own personal characteristics (such as age, sex and professional status) and the methods used on the data obtained.
Partial: Possible sources of influence on the data obtained were mentioned, but the likely impact of the influence or influences was not discussed.
No: There is no evidence of reflexivity in the study report.

Appendix 5: Data extraction forms

Data extraction form for quantitative studies

Author(s)		
Year		
Country		
Publication type		
Reference source		
Study aims		
Design		
Participants	Number	
	Controls (if applicable)	
	Mean age (Standard deviation)	
	Median age (Range)	
	Gender ratio - M:F	
	Ethnicity recorded?	Yes No
	Participant recruitment	
Study period (weeks)		
Length of intervention (hours)		
Study location		
Inclusion criteria		
Exclusion criteria		

Intervention type	Peer support	
	Mentoring	
	Befriending	
	Other	
Outcome(s) measured for carers		
Outcome(s) measured for volunteers		
Measure used to document participant withdrawals.		
Data collection methods used. Were they adequately described?		
How were the data analysed?		
Results and key findings?		
Conclusions		
Study limitations		
Additional comments		

Reviewer	
Date	

Data extraction form for qualitative studies

Author(s)		
Year		
Country		
Publication type		
Reference source		
Study aims		
Methods	Interviews	
	Focus groups	
	Observation	
	Mixed methods (which?)	
	Other	
Participants	Number	
	Mean age (Standard deviation)	
	Median age (Range)	
	Gender ratio – M:F	
	Ethnicity recorded?	Yes No
	Participants recruitment	
Study period (weeks)		
Length of intervention (hours)		

Study location		
Inclusion criteria		
Exclusion criteria		
Intervention type	Peer support	
	Mentoring	
	Befriending	
	Other	
Outcome(s) measured (for both carers and/or volunteers)		
Measure used to document participant withdrawals.		
What data collection methods were used and were they adequately described?		
How were the data analysed?		
Results. What are the key study findings?		
Themes		
Study limitations		

Conclusions	
Additional comments	

Reviewer	
Date	

Appendix 6: PRISMA checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

Appendix 7: Reasons for article exclusion

Article reference	**Database(s) retrieved from**	**Reason for exclusion**
Adams, K. B., Smyth, K. A., & McClendon, M. J. (2005). Psychosocial resources as moderators of the impact of spousal dementia caregiving on depression. *Journal of Applied Gerontology, 24*(5), 475-489.	Embase	Volunteer mentoring was not a type of psychosocial support examined.
Adamski, T., & Alfaro, M. W. (2009). Virtual psycho-educative support groups for caregivers of persons diagnosed with dementia. Caring: *National Association for Home Care Magazine, 28*(8), 44-46.	Embase	Psycho-educative support groups were not volunteer led.
Andren, S., & Elmstahl, S. (2008). Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: A five-year follow-up study. *International Psychogeriatrics, 20*(6), 1177-1192.	Embase	Support group facilitated by a trained counsellor.
Andrews GJ, Gavin N, Begley S, Brodie D. (2003). Assessing friendships, combating loneliness: users' views on a 'befriending scheme' scheme. *Aging & Society, 23*:349–62	Charlesworth et al. (2008), reference list of an included study	Not carers of people with dementia.
Bank, A. L., Arguelles, S., Rubert, M., Eisdorfer, C., & Czaja, S. J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist,*	Embase	Telephone support groups were facilitated by trained therapists.

46(1), 134-138.		
Bass, D., McClendon, M., Brennan, P., & McCarthy, C. (1998). The buffering effect of a computer support network on caregiver strain. *Journal of Aging and Health, 10*(1), 20-43.	Embase PsychInfo Social Sciences Citation Index	Educational training from a trained nurse. No volunteer support.
Beauchamp, N., Irvine, A. B., Seeley, J., & Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist, 45*(6), 793-801.	Medline	Web based multimedia intervention which provides text materials and videos with no human contact.
Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K. M., Lee, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups. A Randomized, Controlled Trial. *Annals of Internal Medicine*, 145, 727-738.	Embase	Carer's received either educational materials or professionally led intensive support.
Bormann, J., Warren, K. A., Regalbuto, L., Glaser, D., Kelly, A., Schnack, J., et al. (2009). A spiritually based caregiver intervention with telephone delivery for family caregivers of veterans with dementia. *Family & Community Health, 32*(4), 345-353.	Medline Embase PsychInfo CINAHL plus Social Sciences Citation Index	Intervention was facilitated by a nurse or social worker. Also, the study looked at carers of people with brain injury and other cognitive impairment; it is not possible to separate the effects of the intervention on carers of people with dementia.
Bourgeois, M. S., Schulz, R., Burgio, L. D., & Scott	From the Pinquart, M., & Sörensen, S. (2006) review	Interventions not delivered by volunteers.

Beach. (2002). Skills Training for Spouses of Patients With Alzheimer's Disease: Outcomes of an Intervention Study. *Journal of Clinical Geropsychology, 8*(1), 53-73.	reference list	
Bowers, H., Macadam, A., Patel, Meena., & Smith, C. (2006). Making a difference through volunteering The impact of volunteers who support and care for people at home. CSV: London.	AgeUK	Doesn't investigate carers of people with dementia specifically.
Branfield, F., & Beresford, P. (2010). A better life: Alternative approaches from a service user perspective. Joseph Rowntree Foundation: York.	Joseph Rowntree Foundation	This article focused on peoples' experiences of being service users. It does not examine an intervention.
Brennan, P. F., Moore, S. M., & Smyth, K. A. (1995). The effects of a special computer network on caregivers of persons with alzheimer's disease. *Nursing Research, 44*(3), 166-172.	Embase PsychInfo AMED	Internet based communication called ComputerLink. Access to volunteer peer support was not available.
Burgio, L., Stevens, A., Guy, D., Roth, D. L., & Haley, W. E. (2003). Impact of two psychosocial interventions on white and african american family caregivers of individuals with dementia. *Gerontologist, 43*(4), 568-579.	CINAHL plus Social Sciences Citation Index	Interventions delivered by trained staff.
Burns, A., Mittelman, M., Cole, C., Morris, J., Winter, J., Page, S., et al. (2010). Transcultural influences in dementia care: Observations from a psychosocial intervention study. *Dementia and Geriatric Cognitive*	Medline Scopus	Intervention consisted of professionally led individual and family counselling.

Disorders, 30(5), 417-423		
Butt, J., & O'Neil. (2004). 'Let's move on' Black and Minority Ethnic older people's views on research findings. Joseph Rowntree Foundation: York.	Joseph Rowntree Foundation	It did not examine the effectiveness of befriending, mentoring or peer support schemes.
Cattan, M., Kime, N., & Bagnall, A-M. (2009). Low-level support for socially isolated older people An evaluation of telephone befriending. AgeUK: London.	AgeUK	An evaluation which focuses on older people in general and not on carers of people with dementia.
Chang, B. L., Nitta, S., Carter, P. A., & Markham, Y. K. (2004). Perceived helpfulness of telephone calls--providing support for caregivers of family members with dementia. *Journal of Gerontological Nursing, 30*(9), 14-21.	Embase Medline	Telephone support delivered by clinical nurses who received specialist training.
Charlesworth, G. (2001). Evidence-based care for carers: What do we mean? *Journal of Dementia Care, 9*(5), 34-36.	Embase	Comment article into evidenced based care for carers.
Charlesworth, G. (2007). Social networks, befriending and support for family carers of people with dementia. *Quality in Ageing, 8*(2), 37-44. 2007.	UK Institutional Repository Search. http://irs.mimas.ac.uk/	Article coming from Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M., Mugford, M., & Poland, F. (2008) which was included.
Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, D., et al. (2008). Befriending carers of people with dementia: Randomised controlled trial. *BMJ, 336*(7656), 1295-1297.	Medline Embase PsychInfo Scopus Social Policy and Practice CINAHL plus Social Sciences Citation Index	Article coming from Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M., Mugford, M., & Poland, F. (2008) which was included.
Charlesworth, G., Burnell,	Social Sciences Citation	Currently a protocol.

K., Beecham, J., Hoare, Z., Hoe, J., Wenborn, J., et al. (2011). Peer support for family carers of people with dementia, alone or in combination with group reminiscence in a factorial design: Study protocol for a randomised controlled trial RID C-2571-2008 RID E-7836-2010 RID G-3011-2011. Trials, 12, 205.	Index UK Institutional Repository Search. http://irs.mimas.ac.uk/	
Chien, W. T., & Lee, I. Y. M. (2011). Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *Journal of Advanced Nursing, 67*(4), 774-787.	Medline Embase PsychInfo	Intervention was delivered by employed case managers.
Chiu, T., Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M., et al. (2009). Internet-based caregiver support for chinese canadians taking care of a family member with alzheimer disease and related dementia. *Canadian Journal on Aging, 28*(4), 323-336.	Medline	Internet support delivered by trained therapists.
Chiu, T. M. L., & Eysenbach, G. (2011). Theorizing the health service usage behavior of family caregivers: A qualitative study of an internet-based intervention. *International Journal of Medical Informatics, 80*(11), 754-764.	Embase	Internet support delivered by trained therapists.
Chu, H., Yang, C. Y., Liao, Y. H., Chang, L. I., Chen, C. H., Lin, C. C., et al. (2011). The effects of a support group on dementia caregivers' burden and depression. *Journal of Aging*	From the Van Mierlo, L. D., Meiland, F. J. M., Van Der Roest, H. G., & Dröes, R. -. (2012) review reference list	Intervention delivered by a master's degree mental health nursing student.

& Health, 23(2), 228-241.		
Clough, R., Manthorpe, J., Green, b., Fox, D., Raymond, G., Wilson, P., Raymond, V., Sumner, K., Bright, L., & Hay, J. (2007). The support older people want and the services they need. Joseph Rowntree Foundation: York.	Joseph Rowntree Foundation	Does not investigate the effectiveness of befriending schemes. This study investigates what people would like more of – one of which was befriending schemes.
Colantonio, A., Cohen, C., & Pon, M. (2001). Assessing support needs of caregivers of persons with dementia: Who wants what? *Community Mental Health Journal, 37*(3), 231-243.	Embase	A survey study asking if carers of people with dementia would be interested in receiving volunteer support.
Coulehan, M. B., Rossie, K. M., & Ross, A. J. (2008). Developing a novel internet-based psychoeducational intervention for dementia caregivers. *AMIA ...Annual Symposium Proceedings / AMIA Symposium.AMIA Symposium,* , 915.	Medline	Evaluation of a carer support website. Not an experimental study.
Cummings, S. M., Long, J. K., Perterson-Hazan, S. & Harrison, J. (1999). The efficacy of a group treatment model in helping spouses meet the emotional and practical challenges of early-stage care-giving. *Clinical Gerontologist, 20*, 29–45.	From the Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J. G., & Newman, S. P. (2001) review reference list	Psychoeducational support group intervention, not volunteer led.
Czaja, S., & Rubert, M. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine, 64*(3), 469-476.	Medline	Telephone support groups were facilitated by trained professionals, including family therapists.
Coulehan, M. B., Rossie, K. M., & Ross, A. J. (2008). Developing a novel internet-	Embase	A poster presentation highlighting research on what carers of people with

based psychoeducational intervention for dementia caregivers. AMIA ...Annual Symposium Proceedings / AMIA Symposium.AMIA Symposium, 915.		dementia want from an internet-based psychoeducational intervention.
Davis, L. L., Burgio, L. D., Buckwalter, K. C., & Weaver, M. (2004). A comparison of in-home and telephone-based skill training interventions with caregivers of persons with dementia. *Journal of Mental Health and Aging, 10*(1), 31-44.	Embase PsychInfo	Intervention delivered by trained staff. No volunteer support.
Davis, J. D., Tremont, G., Bishop, D. S., & Fortinsky, R. H. (2011). A telephone-delivered psychosocial intervention improves dementia caregiver adjustment following nursing home placement. *International Journal of Geriatric Psychiatry, 26*(4), 380-387.	Embase PsychInfo Social Policy and Practice Scopus CINAHL plus Social Sciences Citation Index	Telephone support was delivered by trained therapists.
Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with alzheimer's disease. *Social Science & Medicine, 63*(4), 957-967.	Embase	Support was given and facilitated by trained counsellors.
Ducharme, F., LeVesque, L., Gendron, L., & Legault, A. (2001). Development process and qualitative evaluation of a program to promote the mental health of family caregivers. *Clinical Nursing Research, 10*(2), 182-201.	Embase	Support groups were facilitated by a trained nurse.
Ducharme, F., Lvesque, L.,	PsychInfo	Not befriending, mentoring

& Lachance, L. (2005). Taking care of myself. *Dementia: The International Journal of Social Research and Practice, 4*(1), 23-47.		or peer support.
Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Arguelles, S., Mitrani, V.B., et al. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist, 43*, 521–531.	From the Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010) review reference list	Intervention delivered by trained therapists.
Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing alzheimer's caregiver health II intervention. *Journal of the American Geriatrics Society, 58*(1), 30-37	Medline	Intervention delivered by trained professionals.
Eloniemi-Sulkava, U., Saarenheimo, M., Laakkonen, M. L., Pietila, M., Savikko, N., Kautiainen, H., et al. (2009). Family care as collaboration: Effectiveness of a multicomponent support program for elderly couples with dementia. randomized controlled intervention study. *Journal of the American Geriatrics Society, 57*(12), 2200-2208	Medline	Intervention consisted of multiple types of support including from professionals and peer support groups. It is not possible to separate out the individual contributions of these interventions to the well-being of carers.
Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2004). Psychosocial interventions to reduce depressive symptoms of dementia caregivers: A randomized clinical trial comparing two approaches.	Embase Scopus PsychInfo	Intervention delivered by trained professionals. No volunteer support.

Journal of Mental Health and Aging, 10(4), 337-350.		
Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2007). Efficacy of behavioral interventions for dementia caregivers. *Western Journal of Nursing Research, 29*(8), 944-960.	Medline	Intervention delivered by trained nurses or social workers.
Findlay, R. (2003). Interventions to reduce social isolation amongst older people: where is the evidence? *Ageing & Society, 23*, 647-658.	From the Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011) reference list	This is a review article.
Fung, W. Y., & Chien, W. T. (2002). The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Archives of Psychiatric Nursing, 16*(3), 134-144.	Embase	Support group facilitated by a psychiatric nurse.
Gallagher-Thompson, D., Gray, H. L., Tang, P. C., Pu, C. Y., Leung, L. Y., Wang, P. C., et al. (2007). Impact of in-home behavioral management versus telephone support to reduce depressive symptoms and perceived stress in chinese caregivers: Results of a pilot study. American Journal of Geriatric Psychiatry, 15(5), 425-434.	Social Sciences Citation Index	A Cognitive Behavioural Therapy intervention which was presented in a psychoeducational format.
Gaugler, J. E., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer`s disease during the transition to	Medline	Intervention consisted of counselling and professionally led support groups.

institutionalization? Results from the New York university caregiver intervention study. Journal of the American Geriatrics Society, 56(3), 421-428.		
Gerdner, L. A., Buckwalter, K. C., & Reed, D. (2002). Impact of a psychoeducational intervention on caregiver response to behavioral problems. *Nursing Research, 51*(6), 363-374.	From the Cassie, K. M., & Sanders, S. (2008) review reference list	Carers received a psychoeducational nursing intervention. No volunteer support.
Glueckauf, R. L., & Loomis, J. S. (2003). Alzheimer's caregiver support online: Lessons learned, initial findings and future directions. *NeuroRehabilitation, 18*(2), 135-146.	AMED PsychInfo	Online support was not volunteer led.
Glueckauf, R. L., Ketterson, T. U., Loomis, J. S., & Dages, P. (2004). Online support and education for dementia caregivers: overview, utilization, and initial program evaluation. *Telemedicine Journal and e-Health, 10*, 223–232.	Embase Medline PsychInfo	Online support not delivered by volunteers.
Gonyea, J. G. and Silverstein, N. M. (1991). The role of Alzheimer's disease support groups in families' utilization of community services. *Journal of Gerontological Social Work, 16*, 43–55.	From the Pinquart, M., & Sörensen, S. (2006) review reference list	Support groups not volunteer led.
Goodman, C. (1990). Evaluation of a model self-help telephone program: Impact on natural networks. *Social Work, 35*(6), 556-562.	Embase Medline PsychInfo	Presents the same data as Goodman, C. C., & Pynoos, J. (1990).

Goodman, C. C., & Pynoos, J. (1990). A model telephone information and support program for caregivers of alzheimer's patients. *The Gerontologist, 30*(3), 399-404.	Medline PsychInfo Systematic review reference lists	Intervention delivered by current carers.
Goodman, C. C. (1991). Perceived social support for caregiving: Measuring the benefit of self-help/support group participation. *Journal of Gerontological Social Work, 16*(3-4), 163-175.	PsychInfo	This study is concerned with evaluating two new rating scales on social support and social conflict.
Greene, V. L., & Monahan, D. J. (1989). The effect of a support and education program on stress and burden among family caregivers to frail elderly persons. *The Gerontologist, 29*, 472–477.	From the Sörensen, S., Pinquart, M., Habil, Dr., Duberstein, P. (2002) review reference list	Support groups were professionally guided by nurses and social workers.
Haley, W. E., Brown, S. L., & Levine, E. G. (1987). Experimental evaluation of the effectiveness of group intervention for dementia caregivers. *Gerontologist, 27*(3), 376-382.	Medline Embase	Support groups were led by a clinical psychologist.
Heller, K., Thompson, M. G., Trueba, P. E., John R. Hogg, J. R., & Vlachos, I. W. (1991). Peer Support Telephone Dyads for Elderly Women: Was This the Wrong Intervention? *American Journal of Community Psychology 19*:53-74.	Pillemer & Suitor (2002), reference list of an included study	Not carers of people with dementia.
Hebert, R., Leclerc, G., Bravo, G., Girouard, D., & Lefrancois, R. (1994). Efficacy of a support group programme for care-givers of demented patients in the community: A randomized	From the Acton, G. J., & Kang, J. (2001) review reference list	Intervention delivered by a trained nurse.

controlled trial. *Archives of Gerontology and Geriatrics, 18*(1), 1-14.		
Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions: do they work? *Clinical Psychology Review, 22:*381–440.	Charlesworth et al. (2008), reference list of an included study	This is a review article
Jansson, W., Almberg, B., Grafström, M., & Winblad, B. (1998). The circle model—support for relatives of people with dementia. International Journal of Geriatric Psychiatry, 13(10), 674-681.	Social Policy and Practice Social Sciences Citation Index	Volunteers were being trained to care for people with dementia.
Kahan, J., Kemp, B., Staples, F. R., & BrummelSmith, K. (1985). Decreasing the burden in families caring for a relative with a dementing illness: A controlled study. *Journal of the American Geriatrics Society, 33*(10), 664-670.	From the Brodaty, H., Green, A., & Koschera, A. (2003) review reference list	Intervention was delivered by trained professionals.
Kropf, N. P., & Cummings, S. M. (2008). Evidence-based interventions with older adults: Concluding thoughts. *Journal of Gerontological Social Work, 50*(Suppl 1), 345-355.	Medline	Overview of literature, not an experimental study.
Logsdon, R. G. (2008). Dementia: Psychosocial interventions for family caregivers. The Lancet, 372(9634), 182-183.	Medline PsychInfo	This is a comment article, not a research article.
MacIntyre, I., Corradetti, P., Roberts, J., Browne, G., Watt, S., & Lane, A. (1999). Pilot study of a visitor volunteer programme for community elderly people	From the Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011) reference list	Those that received the volunteer intervention were not carers.

receiving home health care. *Health and Social Care in the Community, 7*, 225-232.		
Martin-Carrasco, M., Martin, M. F., Valero, C. P., Millan, P. R., Garcia, C. I., Montalban, S. R., et al. (2009). Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in Alzheimer's disease patients' caregivers. *International Journal of Geriatric Psychiatry, 24*(5), 489-499.	Medline	Intervention delivered by professionally trained therapists or psychiatrists.
Marziali, E. (2005). Virtual support groups for family caregivers of persons with dementia. *Geriatrics and Aging, 8*(5), 73-74.	Embase	Internet support group was initially led by a professional, followed by the carers supporting each other in the group.
Marziali, E., Damianakis, T., & Donahue, P. (2006). Internet-based clinical services: Virtual support groups for family caregivers. *Journal of Technology in Human Services, 24*(2), 39-54.	CINAHL plus	Online support groups delivered by health professionals initially for ten sessions and then by one of the group members thereafter. It is not possible to separate out the effects of before and after the health professionals delivered the intervention.
Marziali, E., & Garcia, L. J. (2011). Dementia caregivers' responses to 2 internet-based intervention programs. *American Journal of Alzheimer's Disease and Other Dementias, 26*(1), 36-43.	Medline Embase PsychInfo Scopus CINAHL plus Social Sciences Citation Index	Support group intervention supervised by nurses and social workers.
McHugh, J., Wherton, J., & Lawlor, B. (2011). Providing peer-based social support for caregivers of spouses with dementia using telephone conference calls. Alzheimer's	Embase	Excluded as it is a conference paper.

and Dementia.Conference: Alzheimer's Association International Conference, AAIC 11 Paris France.Conference Start: 20110716 Conference End: 20110721.Conference Publication: (Var.Pagings), 7(4 SUPPL. 1), S437.		
Millan-Calenti, J. C., Gandoy-Crego, M., Antelo-Martelo, M., Lopez-Martinez, M., Riveiro-Lopez, M. P., & Mayan-Santos, J. M. (2000). Helping the family carers of alzheimer's patients: From theory...to practice. A preliminary study. *Archives of Gerontology and Geriatrics, 30*(2), 131-138.	PsychInfo	Intervention was both volunteer support and professional support. It is not possible to separate out the effects of the volunteer component alone.
Milne, D., Pitt, I., & Sabin, N. (1993). Evaluation of a carer support scheme for elderly people: The importance of coping. British *Journal of Social Work, 23*, 157–168.	From the Sörensen, S., Pinquart, M., Habil, Dr., Duberstein, P. (2002) review reference list	This study evaluated a respite service for carers.
Mittelman, M. S., Ferris, S. H., Steinberg, G., Shulman, E., Mackell, J. A., Ambinder, A., & Cohen, J. (1993). An Intervention That Delays Institutionalization of Alzheimer's Disease Patients: Treatment of Spouse-Caregivers. *The Gerontologist, 33*(6), 730-740.	From the Van Mierlo, L. D., Meiland, F. J. M., Van Der Roest, H. G., & Dröes, R. -. (2012) review reference list	Counselling intervention delivered by trained professionals.
Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J., Cohen, J. (1995). A comprehensive support program - effect on depression in spouse-	Embase	Intervention was professional counselling

caregivers of ad patients. *Gerontologist, 35*(6), 792-802.		
Mittelman, M. S., Ferris, S. H., Shulman, E., & Steinberg, G. (1996). A family intervention to delay nursing home placement of patients with alzheimer disease: A randomized controlled trial. *JAMA: Journal of the American Medical Association, 276*(21), 1725-1731.	From the Peacock, S. C., & Forbes, D. A. (2003) review reference list	Intervention delivered by trained counsellors.
Mittelman, M. S. (2003). Psychosocial intervention for dementia caregivers: What can it accomplish?. *International Psychogeriatrics, 15*(Suppl 1), 247-249.	Medline Embase	Intervention consisted of professionally led individual and family counselling.
Mittelman, M. S., Roth, D. L., Coon, D. W., & Haley, W. E. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with alzheimer's disease. *American Journal of Psychiatry, 161*(5), 850-856.	From the Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010) review reference list	Intervention delivered by trained professionals.
Mittelman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with alzheimer disease. *Neurology, 67*(9), 1592-1599.	Embase	Intervention consisted of professionally led individual and family counselling.
Morris, L. W., Morris, R. G., & Britton, P. G. (1989). Social support networks and formal support as factors influencing the psychological adjustment of spouse caregivers of dementia	Embase	Interventions examined did not include, befriending, mentoring or peer support.

sufferers. *International Journal of Geriatric Psychiatry, 4*(1), 47-51.		
Morris, R. G., Woods, R. T., Davies, K. S., Berry, J., & Morris, L. W. (1992). The use of a coping strategy focused support group for carers of dementia sufferers. *Counselling Psychology Quarterly, 5*(4), 337-348.	Embase	Educational course delivered by trained professionals.
Murray, E., Kerr, C., Stevenson, F., Gore, C., & Nazareth, I. (2007). Internet interventions can meet the emotional needs of patients and carers managing long-term conditions. *Journal of Telemedicine & Telecare, 13*, 42-44.	CINAHL plus	Internet intervention which combines multiple components, such as decision making, behaviour change and peer support. It is not possible to separate out the impact of the peer support component.
Nichols, L. O., Chang, C., Lummus, A., Burns, R., MartindaleAdams, J., Graney, M. J., et al. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society, 56*(3), 413-420.	Medline	Educational intervention delivered by trained staff.
Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., Mantell, R. (1999). Reducing Caregiver Burden: A Randomized Psychoeducational Intervention for Caregivers of Persons With Dementia. *The Cerontological Society of America, 39*(3), 299-309.	From the Acton, G. J., & Kang, J. (2001) review reference list	Educational workshops delivered by trained professionals.
Pastor, D. K., & Vogel, B. (2011). Supporting community caregiving for a spouse with dementia: Research with implications	Medline	Participants were interviewed about their experiences, no intervention was examined.

for practice. *Home Healthcare Nurse, 29*(7), 443-450.		
Pillemer, K., Landreneau, T., & Suitor, J. J. (1996a). Volunteers in a Peer Support Project for Family Caregivers: What Motivates Them? *American Journal of Alzheimer's Disease, 11*:13-19.	Pillemer & Suitor (2002), reference list of an included study	Investigates motivations for volunteering only.
Pillemer, K., & Suitor, J. J. (1996). 'It takes one to help one': Effects of similar others on the well-being of caregivers. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences, 51*(5), S250-S257.	PsychInfo	This study investigated experiential similarity of people within carers' social networks.
Pillemer, K., Suitor, J. J., Landreneau, L. T., Henderson, C. R. J., & Brangman, S. (2000). Peer support for alzheimer's caregivers: Lessons from an intervention study. In K. [. Pillemer, P. [. Moen, E. [. Wethington & N. [. Glasgow (Eds.), Social integration in the second half of life (pp. 265-286). Baltimore, MD, US: Johns Hopkins University Press; US.	PsychInfo	This study uses the same data presented in Pillemer, K., & Suitor, J. J. (2002), which was included.
Pillemer, K., Suitor, J., & Wethington, E. (2003). Integrating theory, basic research, and intervention: Two case studies from caregiving research. *Gerontologist, 43*, 19-28.	Social Sciences Citation Index	This study uses the same data presented in Pillemer, K., & Suitor, J. J. (2002), which was included.
Robinson, K. (1994). Volunteer interfaith caregivers of kentuckiana (VICK)—a timely concept.	Embase	Volunteers were assisting with a respite service, not mentoring.

Kentucky Nurse, 42(2), 28-29.		
Rook, K. S. (1987). Social support versus companionship: effects on life stress, loneliness, and evaluations by others. *Journal of Personality and Social Psychology, 52*:1132–1147.	Charlesworth et al. (2008), reference list of an included study	Not carers of people with dementia
Rook, K. S., Sorkin, D. H. (2003). Fostering social ties through a volunteer role: implications for older-adults' psychological health. *International Journal of Aging & Human Development, 57*, 313-337.	From the Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011) reference list	Not carers of people with dementia.
Salfi, J., Ploeg, J., & Black, M. E. (2005). Seeking to understand telephone support for dementia caregivers. *Western Journal of Nursing Research, 27*(6), 701-721.	Embase PsychInfo Social Sciences Citation Index	Telephone support provided to carers by healthcare professionals.
Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *Gerontologist, 42*(5), 589-602.	From the Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010) review reference list	This is a review article.
Signe, A., & Elmstahl, S. (2008). Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: Development and effect after 6 and 12 months. *Scandinavian Journal of Caring Sciences, 22*(1), 98-109.	Medline Embase PsychInfo	Intervention delivered by trained professionals.
Sorensen, L. V., Waldorff, F. B., & Waldemar, G. (2008).	Embase Medline	Intervention delivered by trained counsellors. No

Early counselling and support for patients with mild alzheimer's disease and their caregivers: A qualitative study on outcome. *Aging & Mental Health, 12*(4), 444-450.		volunteer support.
Steffen, A. M., Futterman, A., & Gallagher-Thompson, D. (1998). Depressed caregivers: Comparative outcomes of two interventions. *Clinical Gerontologist, 19*(4), 3–15.	From the Sörensen, S., Pinquart, M., Habil, Dr., Duberstein, P. (2002) review reference list	Interventions were psychotherapy or cognitive behavioural therapy. No volunteer support.
Stevens, A. B., Lancer, K., Smith, E. R., Allen, L., & McGhee, R. (2009). Engaging communities in evidence-based interventions for dementia caregivers. Family and Community Health, 32(1 SUPPL.), S83-S92.	Medline PsychInfo	There is only one case study presented and it is not possible to separate out the effects of the volunteer intervention from the support team described.
Strawn, B. D., Hester, S., & Brown, W. S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. Clinical Gerontologist: The Journal of *Aging and Mental Health, 18*(3), 66-69.	Embase PsychInfo	Intervention delivered by graduate students in clinical psychology.
Toseland, R. W., Rossiter, C. M., & Labrecque, M. S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. *The Gerontologist, 29*, 465–471.	From the Sörensen, S., Pinquart, M., Habil, Dr., Duberstein, P. (2002) review reference list	The peer-led and professionally led support groups were for carers of people with 'chronic disabilities'. It is not possible to separate out those who are caring for a person with dementia.
Tremont, G., Davis, J. D., Bishop, D. S., & Fortinsky, R. H. (2008). Telephone-delivered psychosocial	Scopus CINAHL plus	Intervention delivered by Master's level therapists.

intervention reduces burden in dementia caregivers. *Dementia (14713012), 7*(4), 503-520.		
Tremont, G., Davis, J., O'Connor, K., Grover, C., Bishop, D., Ott, B., et al. (2011). Relationship between expectancy/credibility and early response to telephone-based dementia caregiver interventions. Alzheimer's and Dementia. Conference: Alzheimer's Association International Conference, AAIC 11 Paris France.Conference Start: 20110716 Conference End: 20110721.Conference Publication: (Var.Pagings), 7(4 SUPPL. 1), S435.	Embase PsychInfo	Intervention not delivered by peer mentors or volunteers.
Van Mierlo, L. D., Meiland, F. J. M., & Droes, R. -. (2012). Dementelcoach: Effect of telephone coaching on carers of community-dwelling people with dementia. *International Psychogeriatrics, 24*(2), 212-222.	Embase	Intervention delivered by trained professionals. No volunteer support.
Vernooj-Dassen, M., Lamers, C., Bor, J., Felling, A., & Grol, R. (2000). Prognostic factors of effectiveness of a support program for caregivers of dementia patients. *International Journal of Aging & Human Development, 51*(4), 259-274.	Embase	Intervention delivered by trained professionals.
Wallis, L. (2011). REACH VA helps family caregivers of dementia patients. *The American Journal of Nursing, 111*(6), 18.	Medline	Comment article on a previously excluded study (Nichols et al. 2008).

Wang, L., & Chien, W. (2011). Randomised controlled trial of a family-led mutual support programme for people with dementia. *Journal of Clinical Nursing, 20*(15), 2362-2366.	PsychInfo	Support group facilitated by an experienced psychiatric nurse.
Weaks, D., Wilkinson, H., Houston, A., & McKillop, J. (2012). Perspectives on ageing with dementia. Joseph Rowntree Foundation: York.	Joseph Rowntree Foundation	This article focused on people with dementia, not carers of people with dementia.
White, M. H., & Dorman, S. M. (2000). Online support for caregivers: Analysis of an internet alzheimer mailgroup. *Computers in Nursing, 18*(4), 168-179.	Social Sciences Citation Index	Internet forum where carers share information. No volunteer support.
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., et al. (2009). Befriending carers of people with dementia: A cost utility analysis. *International Journal of Geriatric Psychiatry, 24*(6), 610-623.	Medline Embase Social Policy and Practice CINAHL plus Social Sciences Citation Index	Article coming from Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M., Mugford, M., & Poland, F. (2008) which was included.
Yeung, C. M., & Chiu, L. (2004). Effectiveness of a psychogeriatric carer support group for alleviating carers' distress. *Hong Kong Journal of Psychiatry, 14*(4), 24-32+34.	Embase	Professionally led intervention.
Zarit, S. H., Anthony, C. R., & Boutselis, M. (1987). Interventions with care givers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2*(3), 225-232.	From the Acton, G. J., & Kang, J. (2001) review reference list	Intervention delivered by therapists, no volunteer led support.
Zarit, S. H., Anthony, C. R.,	Pillemer & Suitor (2002),	Intervention was

& Boutselis, B. (1989). Interventions With Care Givers of Dementia Patients: Comparison of Two Approaches. *Psychology and Aging* 2:225-32	reference list of an included study	professionally led by trained counsellors.
Zarit, S. H., Femia, E. E., Watson, J., Rice-Oeschger, L., & Kakos, B. (2004). Memory club: A group intervention for people with early-stage dementia and their care partners. *Gerontologist, 44*(2), 262-269.	Medline	The support group is professionally led (social worker and neuropsychologist).

Appendix 8: Systematic review reference list searched

Systematic review reference	Database(s) found	Number of articles identified from the reference list
Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing and Health, 24*(5), 349-360.	Embase	5
Alexy, E. M. (2000). Computers and caregiving: Reaching out and redesigning interventions for homebound older adults and caregivers. *Holistic Nursing Practice, 14*(4), 60-66.	Embase	1
Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664.	CINAHL plus, Embase, Medline, Social Sciences Citation Index	8
Cassie, K. M., & Sanders, S. (2008). Familial caregivers of older adults. *Journal of Gerontological Social Work, 50*(SUPPL. 1), 293-320.	Scopus	2
Chien, L., Chu, H., Guo, J., Liao, Y., Chang, L., Chen, C., Chou, K. (2011). Caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry, 26*(10), 1089-1098.	Embase	1
Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M.	Embase, Social Sciences Citation	5

J. G., & Newman, S. P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health, 5*(2), 120-135.	Index	
Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011). Interventions targeting social isolation in older people: A systematic review. *Bmc Public Health, 11*, 647.	Social Sciences Citation Index	4
Peacock, S. C., & Forbes, D. A. (2003). Interventions for caregivers of persons with dementia: A systematic review. *Canadian Journal of Nursing Research, 35*(4), 88-107.	Embase	2
Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 18*(4), 577-595.	Medline	2
Powell, J., Chiu, T., & Eysenbach, G. (2008). A systematic review of networked technologies supporting carers of people with dementia. *Journal of Telemedicine and Telecare, 14*(3), 154-156.	CINAHL plus, Embase, Medline, Scopus, Social Policy and Practice	5
Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging and Mental Health, 14*(1), 44-56.	Embase	3

Smits, C. H. M., De Lange, J., Dröes, R. -., Meiland, F., Vernooij-Dassen, M., & Pot, A. M. (2007). Effects of combined intervention programmes for people with dementia living at home and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry, 22*(12), 1181-1193.	Medline	0
Sörensen, S., Pinquart, M., Habil, Dr., Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356-372.	Scopus	4
Thompson, C. A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics, 7*, 18.	Embase Medline	1
Zarit, S., & Femia, E. (2008). Behavioral and psychosocial interventions for family caregivers. *American Journal of Nursing, 108*(9 Suppl), 47-53.	Embase	3
Van Mierlo, L. D., Meiland, F. J. M., Van Der Roest, H. G., & Dröes, R. -. (2012). Personalised caregiver support: Effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry, 27*(1), 1-14.	Scopus	5

Appendix 9: Published version of survey of services

Mentoring for carers

Raymond Smith and **Nan Greenwood** report on a survey that aimed to establish how volunteer mentoring schemes are offering support to carers of people with dementia

Volunteer mentoring schemes offer a wide range of services for people with varying needs (Casiday *et al* 2009). Volunteer mentoring can be face-to-face, over the telephone or a combination of both. Increasingly support is also offered over the internet through message boards and forums (Hoey *et al* 2008).

In this article we report the key findings from a survey of volunteer mentoring schemes (befriending, mentoring and peer support) for carers of people with dementia. No identifying information regarding the schemes is provided in order to protect the privacy of those who participated.

Research context

Stewart *et al* (2006) highlighted the positive impact of these schemes when they conducted a study into telephone peer support for carers of people with chronic health conditions. This qualitative study showed that carers had increased coping skills, caregiving competence, decreased feelings of burden and lower levels of loneliness. While this qualitative evidence suggests volunteer mentoring schemes are effective at improving carer well-being, a quantitative study by Charlesworth *et al* (2008) found that the evidence for the effectiveness of befriending schemes for carers of people with dementia was unclear. Not only did the authors report that the uptake of befriending services by carers of people with dementia was low, but also there were no statistically significant effects across the main outcome measures, such as depression, anxiety and quality of life.

More recently, research into peer support for carers of people with dementia (Greenwood *et al* 2013) highlighted reductions in isolation and social exclusion, with one carer highlighting, "So I found that very, very helpful, you know… That's the sort of thing you need, as I say, you get so isolated." Carers also indicated the importance of experiential similarity of the volunteers by being able to talk to someone with similar life experiences: "…I'd talk about the bad moments, and then obviously because she [the peer supporter] cared for her husband, although everybody's different, there's similarities in those things, and it's about how you feel about it, when you're on your own and you're isolated, it's about how you feel."

This survey

This survey of services follows on from a systematic review (Smith & Greenwood 2013) which not only highlighted a lack of research investigating the impact of these schemes, but also revealed contradictory evidence specifically for their effective use for carers of people with dementia. This is despite previous research highlighting volunteer mentoring schemes as having a positive impact in other populations (Dean & Goodlad 1998; Veith *et al* 2006). The review also highlighted the dearth of research into the impact volunteer mentoring has on volunteers.

Following the review, in order to clarify what is actually happening currently, it was decided to interview scheme managers and volunteer coordinators to help us better understand the schemes' aims and what is considered important for good volunteer and carer mentoring relationships.

Methods

A representative from each of nine schemes took part in the survey which ran between September 2012 and January 2013. Six identified themselves as befriending schemes (four face-to-face and two telephone based); two as peer support schemes (one face-to-face and one telephone based), and one as a mentoring scheme (face-to-face).

Either the scheme manager or volunteer coordinator for each scheme completed a questionnaire which looked at: how their scheme operates, the challenges involved and what makes for a strong volunteer mentor and carer relationship. Participants had the option to complete the questionnaire by post, email or over the telephone, depending on which was more convenient for them. The main inclusion criteria were that volunteers delivered the intervention, that carers of people with dementia (as opposed to other conditions) were recipients of the service and that the scheme had not stopped operating more than six months prior to data collection. Qualitative data was content analysed using the qualitative analysis programme Atlas.ti version 6.0 (Murh 2008).

Results

Despite offering different models of volunteer mentoring, the schemes identified four common aims.

Reducing social isolation and improving social integration was seen as a primary aim by six of the nine participants. One volunteer coordinator commented, "It's all about social integration and getting people involved." Another commented "…to reduce the social isolation of carers and to give them a listening ear."

Reducing loneliness was another key aim. Four managers specifically mentioned loneliness, while a further four highlighted ways in which loneliness could be reduced, for example "[A mentor is] someone who is there just for them (carers), to bring friendship, mutual interests, someone to talk to and take an interest in their well-being."

Five managers highlighted the provision of emotional support by volunteers to carers as a key component of volunteer mentoring. One said, "Carers also have the benefit of receiving emotional support and an increase in social contact" and another, "[It] gives them [carers] a listening ear for a general chat or to talk about deeper feelings and issues."

Finally, offering advice and advocacy were seen as an integral part of volunteer mentoring, for example "…to help them (carers) access services and financial entitlements, assist them with housing problems, make calls on their behalf and so on" and, "It also helps people tap into other resources they may not have known about."

It is clear from this that the schemes, while offering volunteer mentoring in different formats, in general have similar aims and are seeking similar outcomes.

Challenges

The main challenges reported were the recruitment and reliability of volunteers. One respondent said, "The volunteers drop out. It is very hit-and-miss," and another: "Recruiting volunteers with adequate experience [is challenging]."

Two managers also suggested that matching volunteers to carers was an issue: "[our scheme has difficulty in] finding suitable volunteers for the role to match (with) the individual carers." Another challenge was raising funds and having adequate resources. Two managers mentioned this as an issue which was preventing growth of the service: "We are not funded for the service and so we are not able to grow" and "Budgeting and raising funds has been difficult."

Matching

Two managers indicated that matching does not take place between carers and volunteers. Of the remaining seven, five argued that matching is "important", "vital" or "essential". One said, "This is really important. There is an initial assessment and carers and volunteers are matched on having similar interests and similar outlooks on life" and another, "It is of prime importance to match the volunteer to the carer."

A number of different reasons for matching were highlighted – including being able to build trust, forming stronger links to each other and based on people's individual requirements. One said, "I see this as vitally important as some carers are quite content with a good gossip while others will need someone who is willing to listen while they pour their heart out." Five managers emphasised that carers will often ask for a volunteer of the same gender.

Despite past research highlighting the importance of matching in the development of successful volunteer and client relationships (Casiday *et al* 2008), it is not apparent if managers are relating its application to any background or theory. Two managers explained they usually go with their experience in knowing what works well. As one said: "There is no theory just a gut feeling after many years of working with volunteers about what relationships will work and what won't."

Prior experience

Only one manager suggested that volunteers having prior caring experience was essential. A further three commented that it was preferable, but not a necessity if the volunteer is seen as suitable for the role. This was highlighted by two managers who stated that, "They do need the right attitude for it and are coming into it for the right reasons," and "Prior caring experience is not essential as long as they have an appreciation for what carers do." This was perhaps a surprising finding, given previous research showing carers find the experiential similarity of the volunteers highly important and valued (Pillemer & Suitor 2002).

Conclusions

While these schemes operate differently in terms of service delivery, they have similar aims and goals. Matching volunteers to carers is something which is seen as very important and is often based on similar backgrounds, interests and hobbies. However, it is also a decision taken by managers or volunteer coordinators based on their feelings of which volunteers and carers are likely to form stronger relationships. Experiential similarity of volunteers was not seen as important to service providers despite previous research indicating its importance. We are currently conducting in-depth research investigating the impact of volunteer mentoring on carers and volunteers using both quantitative and qualitative methods. This will enable us to build a more complete picture regarding the outcomes these schemes offer and highlight areas for further exploration. ■

Acknowledgments

Thanks to Professor Van Drennan and Professor Ann Mackenzie from the Faculty of Health, Social Care and Education, Kingston University and St George's, University of London for their guidance in the development of this study. Thanks also to the service managers and volunteer coordinators who completed the survey. This PhD research is funded by the Kingston University Research and Investment Fund.

References

Casiday R, Kinsman E, Fisher C, Bambra C (2008). *Volunteering and health: What impact does it really have?* Lampeter: University of Wales.

Charlesworth G, Shepstone L, Wilson E, Thalanany M, Mugford M, Poland F (2008). Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial. *Health Technology Assessment* (Winchester, England) 12(4) v.

Dean J, Goodlad R (1998) *The role and impact of befriending*. York: JRF.

Greenwood N, Habibi R, Mackenzie A, Drennan V, Easton N (2013) Peer support for carers: A qualitative investigation of the experiences of carers and peer volunteers. *The American Journal of Alzheimer's Disease and Other Dementias*, 28(6) 617-26.

Hoey LM, Leropoli SC, White VM, Jefford M (2008) Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling* 70(3) 315-337.

Muhr T (2008). ATLAS.ti 6.0 [version 6]. Berlin: Scientific Software Development GmbH.

Pillemer K, Suitor JJ (2002). Peer support for Alzheimer's caregivers: is it enough to make a difference? *Research on Aging* 24(171) 171-91.

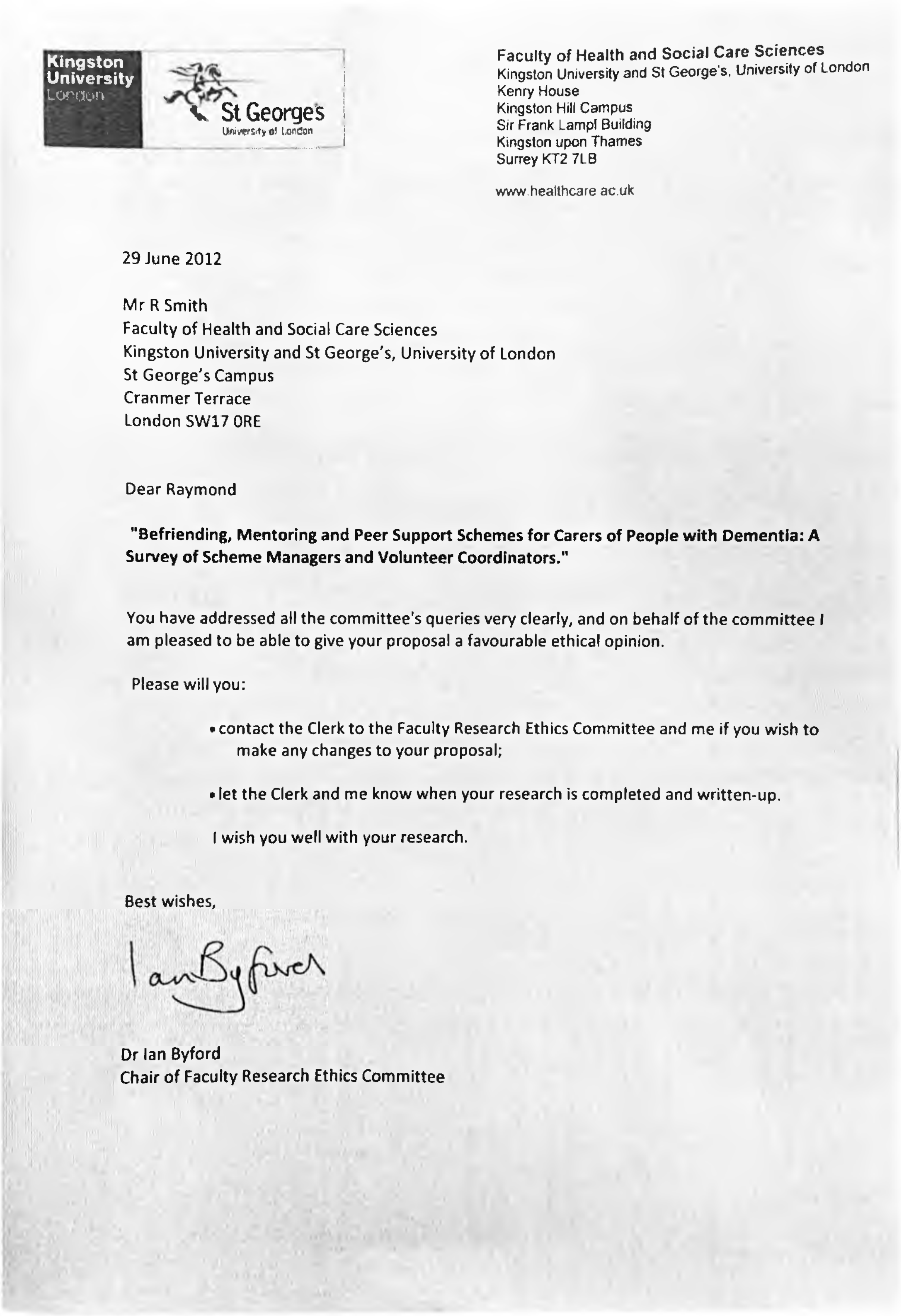
Smith R, Greenwood N (2013) The impact of volunteer mentoring schemes on carers of people with dementia and volunteer mentors: a systematic review. *The American Journal of Alzheimer's Disease and Other Dementias* (online first, Oct 1).

Stewart M, Barnfather A, Neufeld A, Warren S, Letourneau N, Liu L (2006) Accessible support for family caregivers of seniors with chronic conditions: from isolation to inclusion. *Canadian Journal on Aging-Revue Canadienne Du Vieillissement* 25(2) 179-92.

Veith EM, Sherman JE, Pellino TA, Yasui NY (2006) Qualitative analysis of the peer-mentoring relationship among individuals with spinal cord injury. *Rehabilitation Psychology* 51(4) 289-98.

■ Raymond Smith is a PhD student and Dr Nan Greenwood is a Reader in Health and Social Care Service Research; both are based at the Faculty of Health, Social Care and Education, Kingston University and St George's, University of London. To follow up on this article, email Raymond on rs198424@gmail.com

Appendix 10: Survey protocol and ethics approval



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29 June 2012

Mr R Smith
Faculty of Health and Social Care Sciences
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St George's Campus
Cranmer Terrace
London SW17 0RE

Dear Raymond

"Befriending, Mentoring and Peer Support Schemes for Carers of People with Dementia: A Survey of Scheme Managers and Volunteer Coordinators."

You have addressed all the committee's queries very clearly, and on behalf of the committee I am pleased to be able to give your proposal a favourable ethical opinion.

Please will you:

- contact the Clerk to the Faculty Research Ethics Committee and me if you wish to make any changes to your proposal;
- let the Clerk and me know when your research is completed and written-up.

I wish you well with your research.

Best wishes,

Ian Byford

Dr Ian Byford
Chair of Faculty Research Ethics Committee

APPLICATION FORM FOR ETHICAL REVIEW RE4	**Faculty reference:**

SECTION A

Project title:

Befriending, Mentoring and Peer Support Schemes for Carers of People with Dementia: A Survey of Scheme Managers and Volunteer Coordinators

Name of the lead applicant:

Name (Title / first name / surname):	Mr Raymond Smith
Position held:	PhD student
Department/School/Faculty:	Faculty of Health and Social Care Sciences
Telephone:	(020) 8266 6193
Email address:	K1163824@kingston.ac.uk

Name of co-applicants:

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	
Telephone:	
Email address:	

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	

Telephone:	
Email address:	

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	
Telephone:	
Email address:	

Is the project

Student research	Yes	■	No	☐
KU Staff research	Yes	☐	No	☐
Research on KU premises	Yes	☐	No	☐

If it is STUDENT research: Course: ____PhD______________________

Supervisor/DoS: ______Dr Nan Greenwood________________

SECTION B

Has approval for the project already been granted by another ethics committee?

Yes ☐ No ■

If **NO**, proceed to **Section C**;

If **YES**, please complete the rest of this section before going to the declaration in **Section D**:

Name of the committee: ___________________________________ Date of approval: _________

Please attach the submission made to that committee, together with the approval letter. The Faculty Research Ethics Committee (FREC) may require further information or clarification from you and you should not embark on the project until you receive notification from the FREC that recognition of the approval has been granted.

SECTION C

Briefly describe the procedures to be used in this research involving human participants

This study is a telephone survey of managers and volunteer coordinators of mentoring services for carers of people with dementia. Potential participants will be sent an information letter with a brief background to the study, including what the study involves and that the letter will be followed up with a telephone call. During the follow up phone call, potential participants will be asked if they have received and read through the letter. If they have they will be asked if they would like to take part in the survey. If they have not read the letter, the researcher will explain what it contains and the purpose of the study and asked if they would like to participate. If they do wish to participate, then a time convenient to both them and the researcher will be made in order to conduct a telephone interview. Participants will be given the option of completing the questionnaire by email or post if it is more convenient to them. The telephone interview will be recorded and then transcribed if the participant agrees. If not, then responses to questions will be written down. If they decline to be interviewed they will be thanked for their time and the call ended.

Summarise the data sources to be used in the project:

Data will be collected through the administration of a telephone survey. The questionnaire includes 31 questions which will be asked to all participants. (However, further questions or prompts could be asked to elicit more information with regards to the initial question asked, for example: the question 'what are the positive aspects of the service' could lead to a question asking the participant to describe what impact that positive aspect has had on the service.) Interviews with participants will be conducted over the telephone and recorded. The recordings will then be transcribed before being destroyed.

Estimate duration of the project (months):

____Four______________________________

State the source of funding:

________N/A______________________________________

Is it collaborative research?

Yes ☐ No ■

If YES, name of the collaborator institutions:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________

Provide a brief project description (max. 150 words). This should be written for a lay audience

This is a telephone survey of managers or volunteer coordinators of befriending, mentoring and peer support schemes for carers of people with dementia in London and South East England. Services will be identified through internet searching and asking contacted services of they know of any other similar services. The managers or volunteer coordinators of the service will be interviewed to investigate the differences between how the schemes are run, experiences managers have had in their roles, and how schemes impact on volunteers and carers. All participants will be informed their responses are confidential and that interviews will be anonymised and only identified by a code. They will be informed that they can withdraw at any time. Interviews will be conducted using a semi-structured questionnaire containing 31 questions allowing both qualitative and quantitative data to be collected. Quantitative data will be recorded in the Statistical Package for the Social Sciences (SPSS). Qualitative data will be inputted into a Word table for later analysis. Data will be analysed using descriptive statistic and thematic analysis. Approximately five schemes from each type of mentoring project will be contacted, leading to an expected total of 15 completed questionnaires. Fifteen invitation letters will be sent out initially. Once responses have been sought from the initial fifteen services contacted, further letters will be sent out until fifteen completed questionnaires have been reached.

Risk Assessment: Does the proposed research involve any of the following?

Children or young people under 18 years of age?	Yes		No	
If YES, have you complied with the requirements of the CRB?	Yes		No	

People with an intellectual or mental impairment, temporary or permanent?	Yes		No	

People highly dependent on medical care, e.g., emergency care, intensive care, neonatal intensive care, terminally ill, or unconscious?	Yes		No	

Prisoners, illegal immigrants or financially destitute?	Yes		No	

Women who are known to be pregnant?	Yes		No	

Will people from a specific ethnic, cultural or indigenous group be targeted in the proposed research?	Yes		No	

Assisted reproductive technology?	Yes		No	

Human genetic research?	Yes		No	

Epidemiology research?	Yes		No	

Stem cell research?	Yes		No	

Use of environmentally toxic chemicals?	Yes		No	

Use of ionizing radiation?	Yes		No	

Ingestion of potentially harmful or harmful dose of foods, fluids or drugs?	Yes		No

Contravention of social/cultural boundaries?	Yes		No

Involves use of data without prior consent?	Yes		No

Involves bodily contact?	Yes		No

Compromising professional boundaries between participants and researchers?	Yes		No

Deception of participants, concealment or covert observation?	Yes		No

Will this research significantly affect the health* outcomes or health services of subjects or communities?	Yes		No

Note* health is defined as not just the physical well-being of the individual but also the social, emotional and cultural well-being of the whole community.

Is there a significant risk for enduring physical and/or psychological harm/ distress to participants?	Yes		No

Does your research raise any issues of personal safety for you or other			

researchers involved in the project? (especially if taking place outside working hours or off University premises)	Yes		No	■

Will the research be conducted without written informed consent being obtained from the participants?	Yes	■	No	

Will financial/in kind payments (other than reasonable expenses and compensation for time) be offered to participants? (Indicate in the proposal how much and on what basis this has been decided)	Yes		No	■

Is there a potential danger to participants in case of accidental unauthorised access to data?	Yes		No	■

N.B. If you have answered YES to any of these questions, you should address them fully in your project proposal and show that there are adequate controls in place.

Storage, access and disposal of data

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

After the interview has taken place it will be immediately transcribed by the researcher onto a university computer. This is password protected and only the researcher has access to the files. If it is not possible to transcribe the recording on that day, the recording device will be secured in a locked cabinet on the university site that only the researcher has access to. No transcripts will be taken off university premises. Once the interview has been transcribed it will be deleted from the recording device. The transcripts will be kept on a password protected computer until they have been reviewed for any identifying information, which if found will be deleted. It may be important in future research related to the PhD to go back and review the

interviews. As such, the anonymised transcripts will be kept securely on the password protected computer for a maximum of 5 years before being destroyed.

SECTION D

To be signed by all applicants

Declaration to be signed by the applicant(s) and the supervisor (in the case of a student):

- I confirm that the research will be undertaken in accordance with the Kingston University *Guidance and procedures for undertaking research involving human participants*

- I will undertake to report formally to the relevant Faculty Research Ethics Committee for continuing review approval.

- I shall ensure that any changes in approved research protocols or membership of the research team are reported promptly for approval by the relevant Faculty Research Ethics Committee.

- I shall ensure that the research study complies with the law and University policy on Health and Safety.

- I confirm that the research study is compliant with the requirements of the Criminal Records Bureau where applicable.

- I am satisfied that the research study is compliant with the Data Protection Act 1998, and that necessary arrangements have been, or will be made with regard to the storage and processing of participants' personal information and generally, to ensure confidentiality of such data supplied and generated in the course of the research.

(Note: Where relevant, further advice should be sought from the Data Protection Officer, University Secretary's Office)

- I shall ensure that the research is undertaken in accordance with the University's Single Equality Scheme.

- I will ensure that all adverse or unforeseen problems arising from the research project are reported immediately to the Chair of the relevant Faculty Research Ethics Committee.

- I will undertake to provide notification when the study is complete and if it fails to start or is abandoned;

- (For supervisors, *if the applicant is a student)* I have met and advised the student on the ethical aspects of the study design, and am satisfied that it complies with the current professional (*where relevant),* departmental and University guidelines. I accept responsibility for the conduct of this research and the maintenance of any consent documents as required by this Committee.

- I understand that failure to provide accurate information can invalidate ethical approval.

Signature of lead applicant: ...Raymond Smith..........
Date:.........14/05/2012............

For Faculty of Health and Social Care Sciences research office use only:

Date of receipt:

Date of FREC:

Approved at FREC : Yes No

Rejected:

CHECKLIST

Please complete the checklist and attach it to your application:

Project title: Befriending, Mentoring and Peer Support Schemes for Carers of People with Dementia: A Survey of Scheme Managers and Volunteer Coordinators

Lead Applicant: Raymond Smith

Date of application: 14/05/2012

Before submitting this application, please check that you have done the following: *(N/A = not applicable)*	**Applicant**			*Committee use only*		
	Yes	**No**	**N/A**	**Yes**	**No**	**N/A**
All questions have been answered	■					

All applicants have signed the application form	■					
The research proposal is attached	■					
Correspondence from other ethics committees is attached			■			
Informed Consent Form is attached			■			
Participant Information Sheets are attached	■					
All letters, advertisements, posters or other recruitment material to be used are attached	■					
All surveys, questionnaires, interview/focus group schedules, data sheets, etc, to be used in collecting data are attached	■					
Reference list attached, where applicable	■					

Befriending, Mentoring and Peer Support Schemes for Carers of People with Dementia: A Survey of Scheme Managers and Volunteer Coordinators

Protocol for a Telephone Survey Study

The following is a research protocol for a telephone interview survey of managers and volunteer coordinators of befriending, mentoring and peer support schemes for carers of people with dementia in London and South East England. For consistency, the term 'mentoring' will be used when referring to befriending, mentoring and peer support schemes collectively.

Background

Why are these schemes becoming increasingly common?

With the number of people living with dementia increasing (Ferri et al. 2005) and subsequently the number of people taking on caring roles also on the rise (Lewis et al. 2009), the UK government is investigating ways to keep carers supported as a way of reducing the cost of dementia care to the economy (Luengo-Fernandez et al. 2010). The English government recently updated its social policy regarding the welfare for carers of people with dementia through The National Dementia Strategy (Department of Health, 2009), which highlighted that the development of peer support networks for carers was a high priority (p. 5). It also stated that "third sector services commissioned by health and social care" would be supported in the development of these schemes (p. 5).

The impact and effectiveness of mentoring schemes

The different types of mentoring schemes (befriending, mentoring and peer support) are used across a wide range of services for people with different needs. The positive impact of peer support was also highlighted by Stewart et al. (2006) who conducted a study into telephone peer support for carers of people with chronic health conditions. The qualitative findings from this study showed that carers had increased coping skills, care giving competence, decreased feelings of burden and lower levels of loneliness. Whilst there is qualitative evidence for the effectiveness of mentoring schemes at improving carer well-being (Stewart et al. 2006), a quantitative study Charlesworth et al. (2008) found that the evidence for the effectiveness of befriending schemes for carers of people with dementia is unclear. Not only did they report that the uptake of befriending services by carers of people with dementia was low, but also there were no statistically significant effects across the main outcome measures, such as depression, anxiety and quality of life.

Why do people volunteer and what keeps them volunteering?

There are number of reasons why people choose to volunteer and continue to do so. For example, Prouteau and Wolff (2008) showed a possible reason why people choose to volunteer was that they want to make friends by increasing their social circle through volunteer work. There is also evidence to suggest that volunteers were more likely to continue volunteering if they had access to a volunteer co-ordinator either in person or over the telephone (Fyvie-Gauld & de Podesta, 2007), with Musick and Wilson (2003) highlighting that volunteers were having more access to psychological resources as a possible explanation. The studies cited above indicate that volunteering can be seen as highly beneficial for people who are socially isolated by increasing positive feelings about themselves. These studies suggest that the impact mentoring schemes are having on the volunteers who deliver the intervention needs to be clearly understood in order for the volunteers to gain the maximum benefit for themselves from the experience.

What makes for a successful volunteer and carer relationship?

There is some evidence to suggest that a carer and volunteer relationship will develop more quickly and be longer lasting if matching for similarity beforehand has taken place (Andrews et al. 2003). This is supported by Dean and Goodlad (1998) who conducted a study looking at befriending services. It was shown that matching of volunteers and service users on issues such as shared interests, was seen a very important to the success of befriending relationships. In contrast, the findings by Andrews et al. (2003) and Dean and Goodlad (1998) conflict with those of Sabir et al. (2003), who conducted a study to explore whether matching volunteers and carers for similarities, such as age, employment status, marital status and psychological well-being, helped with the success of building successful peer support relationships in carers of people with dementia. The results showed that there were no relationships between volunteer and carer similarity and the success of the peer support intervention and it was concluded that peer support schemes do not need to develop extensive matching criteria.

Importance of this study

There is little research on what these schemes aim to achieve, how they are developed and what managers and volunteers coordinators have experienced in their roles; for example, in recruiting volunteers. The research that is available offers contradictory results in terms of what makes for a successful mentor and carer relationship, and also how effective the schemes are at improving carer well-being. Therefore it is important to investigate how these schemes are operating and how the volunteers are delivering the intervention in order to understand the variations among them and inform future areas of research.

Research aims and questions

The aims of this study are to understand the range and differences between the schemes currently and recently provided. For example, the reasons for setting up the service, the manner in which they operate and also what outcomes are intended for carers and, if appropriate, volunteers. It will also highlight how volunteers are recruited and any issues there are in retaining them.

Research questions:

1. What is the range of types of schemes currently and recently (up to six months prior to data collection) provided in London and South East England?
2. What is the range of funding and who commissioned the schemes?
3. What is the range of outcomes and benefits the schemes are expected to deliver to carers and volunteers?
4. What experiences and challenges have the schemes faced in recruiting and keeping volunteers?
5. What criteria are used for the acceptance of volunteers?
6. What methods are used, and on what basis, to assign volunteers to carers?
7. What are the costs per carer for running the schemes?
8. What types of support are offered to volunteers?

Methods

Study design

A telephone interview survey will be conducted in London and South East with the managers or coordinators of mentoring services. Copies of the questionnaire (appendix 2) will also be sent over email and in the post if participants prefer. Initially services will be identified through internet searching, with the aim of asking contacted services if they know of others and building a list of contactable services. Approximately five schemes from each type of mentoring project will be contacted, leading to an expected total of 15 completed questionnaires. Fifteen invitation letters will be sent out initially. Once responses have been sought from the initial fifteen services contacted, further letters will be sent out until fifteen completed questionnaires have been reached.

Inclusion/exclusion criteria

Inclusion criteria:

- The scheme must offer a befriending, mentoring or peer support service for carers, including carers of people with dementia.
- Volunteers deliver the intervention.
- The schemes address the needs of carers.

Exclusion criteria:

- Unable to identify if carers of people with dementia are receiving the service.
- If paid employees are delivering the intervention.
- If carers are paying for the service.
- If the scheme has stopped operating more than six months prior to data collection.

Study procedure

Once a service has be identified, an information letter (appendix 1) will be sent out to the manager of the service which will introduce the study, what participation will involve and also that the letter will be followed up with a phone call approximately one week, but within two weeks, after delivery. The researcher will explain the reason for the phone call and ask if he can speak to the person who the letter was addressed to. The potential participant will be asked if they received and have read the letter and if they would like to participate in the study and if so, when would be a convenient time for the interview to take place. If they have not read the letter, the researcher will explain what it contains and the purpose of the study. If the potential participant declines to take part they will be thanked for their time and the call will be ended. All participants will be informed their responses are confidential and that interviews will be anonymised and identified by code. Telephone calls are expected to mostly take place between 9am and 5pm Monday to Friday, although if a scheme manager or volunteer coordinator would prefer to complete the interview outside if these times exceptions will be made. The telephone interviews will be recorded with a digital recorder and this will be explained to participants before the interview begins. If the participant declines to the interview being recorded, their answers will be written down underneath each question. Before moving on to the next question care will be taken to ensure all information from the response has been documented. For those managers who are unable to be interviewed by telephone, they will be offered an email or hard copy posted to them. The information returned in this format will be treated in the same manner as that from telephone interviewing.

Nonresponse

The number of phone calls made will be documented. This will include phone calls which were unanswered, participant refusal, non-response and the schemes not meeting the inclusion criteria described above. Several attempts to contact the scheme manager will be made before it is recorded as a non-response. Those who do not wish to participate will be thanked for their time and the call will be ended. Data will be collected on the number of services called which have stopped operating, and a questions asked (if someone is contactable from the parent organisation) for the reasons for the closure of the service.

Data Collection

Questionnaire

The questionnaire contains a mixture of closed and open ended questions. For example, it will seek to identify numerical details such as the amount of volunteers each scheme has and how many clients. The questionnaire is expected to take approximately 30 minutes to complete over the telephone, which the participants will be informed of before starting. The length of time taken to complete the questionnaire will be finalised after piloting has been completed. For those potential participants who would rather not speak over the telephone and fill one in by hand or email, hard copies will be sent to them (with a stamped addressed envelope) with a request that they try to return the questionnaire within a two week timeframe.

Piloting the questionnaire

The survey questionnaire will be piloted in order to highlight any problems with specific questions in terms of being clearly understood. It will be piloted on co-researchers and also managers or volunteer coordinators from relevant organisations. Approximately five people will be asked to assist in the piloting of the questionnaire. It will also identify if the questions being used are fully appropriate for managers or volunteer coordinators and will receive the most comprehensive responses with which to answer the predefined research questions. There will also be the opportunity for participants to highlight any questions they think should be asked which are missing from the questionnaire.

Data Management

Quantitative data, such as number of volunteers and carers will be recorded in the Statistical Package for the Social Sciences (SPSS). Qualitative data will be inputted into a Word table for later analysis.

Data Analysis

Quantitative data will be entered into a table and analysed with descriptive statistics and qualitative data will be content analysed.

Ethical Considerations

Ethical approval will be sought from the Kingston University Faculty Research Ethics Committee (FREC). The ethical considerations highlighted in this section were documented using the Economic and Social Research Council Framework for Research Ethics (ESRC, 2010) as a framework.

Participants

The participants in this study will be mangers or volunteer coordinators of mentoring schemes. They will be fully informed of the purpose of the research with an information letter sent beforehand. This will then be repeated verbally during the initial phone call informing them of what the interview will consist of in terms of the estimated length of time it may take and number of questions that will be asked. It will be stated that they are under no obligation to answer any or all of the questions and do not have to give a reason for doing so.

Confidentiality

All services which agree to take part in the survey will be told before participation that their answers are confidential. Only the name of contacted organisation will be documented to make sure none are called twice. They will also be informed that only the type of service operating (befriending, mentoring or peer support) and general location (London or South East England) will be documented and used in any future publication or research.

Informed consent

Informed consent for this study will be obtained verbally prior to starting the data collection. Participants will be asked that they consent to taking part and that they are doing so voluntarily and are under no obligation to continue. Participants will not be coerced into taking part or be paid for taking part in the study.

Right to withdraw

The interviewee will be informed prior to starting the interview that they can withdraw at any time without giving a reason and the information they have provided will be destroyed if they wish.

Potential problems

Below are a number of anticipated problems which could be encountered when conducting the study. Where possible, the measures to be taken to try and reduce the chance of such issues occurring have been identified.

- Finding relevant services and piloting of the questionnaire may take longer than anticipated if it becomes difficult to find enough of the schemes willing to participate. If ten or less schemes are identified, the study recruitment area will be extended to mentoring schemes outside of London and South East England.
- Participants will be assured of confidentiality so they can speak freely about the service.
- Some managers may not know some aspects of the schemes, such as the rationale for its implementation and development. If this occurs, they will be asked if anyone else is available in order to answer that question. If not, then the answer to the question will be documented as 'not known'.
- There could also be difficulty in contacting managers or finding the appropriate time to speak with them. As such, there will be flexibility offered in terms of when a call

back can be given or if desired, the managers can call back at a time convenient for them.

- Primarily services for carers of people with dementia will be contacted, but if too few are found, services which include carers of people with dementia but do not support them exclusively will be contacted.

Time scale and presentation of findings

The expected timescale for the completion for the study is four months from the completion of this protocol and gaining ethics approval. The steps to completion are: ethical approval, piloting of the questionnaire, data collection, data analysis and the writing up of the findings. This protocol was developed using the guidelines issued by the World Health Organization (WHO, 2012: recommended format for a research protocol).

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Appendix 11: Survey questionnaire

The questionnaire will take approximately 20 minutes to complete. The interview will be recorded and the recording will be destroyed once it has been transcribed. All answers given are completely anonymous. You may ask to stop for a break or withdraw from the study at any time.

Address of the organisation contacted:
Is address correct at the time of calling?
Best contact details:
Time and date of call:
Title of person spoken to:
Has the participant given oral consent agreeing to participate?
Has the participant given consent to the interview being recorded?

Questions about the scheme:

1. How long has the scheme been operating?
2. What does the scheme aim to achieve?
3. Are there a set number of weeks or months the befriending/mentoring/peer support lasts, or not?
4. How long do befriending/mentoring/peer support sessions usually last?
5. If known, what is the cost of the service per carer supported?
6. Are there any challenges you have come across whilst running the scheme?

Questions about volunteers:

1. How many volunteers do you have at the moment for the befriending/mentoring/peer support scheme?
2. Are the volunteers given training, or not? If so, what does training entail?
3. Do the volunteers receive supervision, or not?
4. Can you tell me what supervision entails? (e.g. Held in a group, individually, with or without a facilitator? How often?)
5. Is prior caring experience an inclusion criteria for recruiting volunteers?
6. Do volunteers work a set amount per week, or not?
7. Is there flexibility about when and the amount of time expected to be given?
8. How do you recruit volunteers?
9. Have you had any difficulties in recruiting volunteers or not?
10. Have you had any difficulties retaining volunteers, or not?
11. Do volunteers develop friendships with the carers, or not?
12. Do volunteers give any reasons for deciding to become befrienders/mentors/peer supporters?
13. Could you describe your typical volunteer in terms of age and gender?

Questions about carers of people with dementia:

1. How many carers are currently receiving the service?
2. How do you recruit carers?
3. Have you had any difficulty in recruiting carers to the scheme?
4. How often do carers drop out of the scheme, and if they do, why?
5. Are the carers matched with volunteers? And if so is this seen as important? In what ways are they matched? Is there a theory behind its use, or not?
6. Can you describe your typical carer receiving the service in terms of age and gender?

We have reached the end of the questionnaire, thank you very much for taking part in this study.

Would you be interested in participating in any future research?

Would you like to be sent a summary of the findings?

Appendix 12: Survey participant information letter

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
Cranmer Terrace
London SW17 0RE

www.healthcare.ac.uk

Dear

Re: Telephone Survey of Befriending, Mentoring and Peer Support Services

We are currently investigating mentoring services for carers and are asking you if you would like to help us with a study. The telephone survey is being conducted as part of PhD research into befriending, mentoring and peer support services. We have identified your service through [to add]. ....

These types of services are relatively new and the study is investigating:

- the differences and similarities between the different types of mentoring schemes
- the experiences of managers or volunteer coordinators in operating the service with volunteers in terms of, for example, recruitment of volunteers and carers.

We are asking for your help through answering some questions in confidence over the telephone about your befriending/mentoring/peer support[*delete as appropriate*] service. We estimate the survey will take approximately 30 minutes to complete. If you would prefer to participate in another way, a copy of the questionnaire can be emailed or sent to you (with a stamped addressed envelope).

Any information you provide will be kept anonymous. In reporting the project, no information will be made available which will enable the reader to identify who the respondent was or which service is being referred to.

After this letter has been sent out, Raymond Smith will follow up with a phone call to see if you would like to take part and if so, to arrange an appropriate time to conduct the interview. Your participation is completely voluntary and you can withdraw from the study at any time without reason. The information you have provided up to that point would destroyed if you so wished.

All those who take part will be offered a summary of the findings from the study.

If you have any questions or would like to opt out in advance, please contact Raymond Smith using the details below. For any questions or comments about our research in general, please contact Dr Nan Greenwood on the email address below.

Thank you for your time and I look forward to talking with you.

Yours sincerely

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Appendix 13: Summary of survey findings for participants

Befriending, Mentoring and Peer Support Schemes for Carers of People with Dementia: A Survey of Scheme Managers and Volunteer Coordinators

Summary of Findings

February 2013

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
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With the number of volunteer peer support schemes for carers of people with dementia likely increase over the coming years (National Dementia Strategy, 2009), further research into how they operate and the differences between them is warranted. This survey of scheme managers and volunteer coordinators was carried out between September 2012 and January 2013. In total, nine managers and volunteer coordinators of face-to-face and telephone befriending, mentoring and peer support schemes took part.

This survey forms part of a larger body of research into the different types of mentoring and follows on from the findings of a systematic review. The next steps will be to investigate outcomes for carers and volunteers, and to improve understanding of the types of bonds which are formed during a mentoring relationship.

Below is a summary of the findings from the survey study.

1. What do the schemes aim to achieve?

The schemes surveyed aimed to achieve a wide ranging number of outcomes for carers. However, analysis of the qualitative data revealed four goals which were common to the majority of the managers and volunteer coordinators.

1.1. Social isolation and social integration

One of the most common aims was to reduce the sense of social isolation and improve social integration for carers. Six of the nine schemes stated this as primary aim. One scheme manager commented that the scheme aims to *"...reduce the social isolation of carers and to give them a listening ear for a general chat or to talk about deeper feelings and issues."* Another manager suggested *"It's all about social integration and getting people involved."*

1.2. Loneliness

Reducing loneliness for carers was another key aim for the schemes. Four managers specifically mentioned loneliness, whilst a further four highlighted ways in which loneliness could be reduced, for example "... *someone who is there just for them* (carers), *to bring friendship, mutual interests, someone to talk to and take an interest in their well-being."*

1.3. Emotional support

Providing emotional support to carers was seen as a key component of a mentoring intervention. This was indicated by five managers, for example "*...carers also have the benefit of receiving emotional support and an increase in social contact*" and through ways in which emotional support may be received, "*...give them* (carers) *a listening ear for a general chat or to talk about deeper feelings and issues."*

1.4. Advice and advocacy

Advice and advocacy was mentioned by four managers and is something which could be an integral part of volunteer mentoring, "*...to help them* (carers) *access services and financial entitlements, assist them with housing problems, make calls on their behalf, etc...*" and "*...it also helps people tap into other resources they may not have known about.*"

2. Differences and similarities between the schemes

mentioned by five managers was the recruitment of volunteers, "*there is a lot of interest but a large drop-out between initial*

Whilst there were many similarities and difference between the schemes, three key areas were identified.

2.1. Length of time schemes have been operating

Most of the schemes contacted as part of this survey were fairly new, with the length of time in operation ranging from 1 to 10 years, with an average of 4.9 years. Most commonly managers reported their scheme as being approximately 5 years old.

2.2. Length of time befriending, mentoring or peer support lasts

- **Per session**

The amount of time each session lasts varied greatly, with three schemes having no fixed length of time. Among the schemes session time lasted from between ten minutes to two hours, with an average of 73 minutes. Most commonly, managers reported mentoring sessions lasted one or two hours.

- **Intervention length**

This is an area where the majority of schemes reported near identical responses. Eight out of nine suggested that there was no fixed length of time the intervention lasted and that it is given as long as the carer needs it. One scheme offered the intervention to carers for a period of 12 weeks before the volunteer would go on to see another carer.

2.3. Challenges manager and volunteer coordinators have faced

Many of the schemes share similar challenges and difficulties. The main issue volunteers supervision by telephone or supervision through email contact. One scheme suggested that volunteers receive emotional support as part of the supervision process.

3.3. Prior caring experience

interest and final placement". The reliability of volunteers was also seen as a common issue, "*...the volunteers drop out. It is very hit and miss with the volunteers*". Further, two managers suggested that matching volunteers to carers was an issue, "(difficulty in) *finding suitable volunteers for the role to match* (with) *the individual carers*." Only one manager stated that recruiting carers was difficult, "*...getting new carers to the service is becoming increasingly challenging, this is partly due to other services withholding*."

Raising funds and having adequate resources was mentioned as an issue by two managers which was preventing growth of the service, "*We are not funded for the service and so we are not able to grow*" and "*Budgeting and raising funds has been difficult*".

3. Volunteers

3.1. Training

All nine schemes surveyed offered new volunteers training. The type of training given and the length of time taken for completion varied. Specifically, training in safeguarding, developing boundaries and vulnerable adult protection were most commonly mentioned. Two managers also stated that volunteers have the opportunity to discuss further training needs in their monthly supervision.

3.2. Supervision

Seven of the nine schemes offered their volunteers some form of supervision. Most commonly this was conducted individually with the scheme manager or volunteer coordinator, however two schemes had monthly group supervision which included all volunteers. Further, two schemes offered

3.6. Friendships between volunteers and carers

Eight of the nine managers indicated that friendships do occur between volunteers and carers, with one commenting that it is not

One of the nine managers interviewed reported that prior caring experience was essential for volunteers. A further three commented it was preferable, but not a necessity if it is felt the volunteer is suitable for the role. This was highlighted by two mangers who stated that " *They do need the right attitude for it and are coming into it for the right reasons"* and "*Prior caring experience is not essential as long as they have an appreciation for what carers do*".

3.4. How the volunteers provide the service

Overall, there was a general consensus that the volunteers are given as much flexibility as possible over when and the amount of time that was expected to be given. However, one manager explained that the volunteers preferred a more structured approach, "*...volunteers prefer to have a set time and day*".

3.5. Volunteer recruitment

Volunteer recruitment is undertaken in a variety of different ways. The most common and successful methods were highlighted as local advertising through leaflet drops to GP surgeries and other community organisations, and through word of mouth. Other avenues of recruitment included the use of websites such as 'Do-It.org.uk', holding events, mail outs of newsletters and by contacting carers who have previously used the service.

encouraged, "*No, we do not encourage this. Once the mentoring relationship is over the mentor doesn't see the carer again.*" Of the remaining eight, two said that it does happen but that it is not encouraged and there have to be boundaries. The final six suggested friendships develop naturally over time and the carer and volunteer continue to see each other after the intervention has ended.

4. Carers

4.1. Carer recruitment

Carers are recruited in many of the same ways as volunteers, however there are a number of differences. The main pathway for referrals, mentioned by six managers, comes from social services, GP surgeries and Admiral Nurses. This was achieved by a combination of networking and through "*...professionals who mention the service to carers.*" Word of mouth, leaflet drops and advertising were also mentioned as ways of gaining self referrals.

4.2. Carer withdrawal from the scheme

The intervention normally comes to a natural end, for example, "*If the PWD* (person with dementia) *died, has gone into a residential care or they feel they no longer need it*". The intervention rarely ends whilst the person is still caring. However, one manager of a telephone befriending scheme stated that sometimes carers do not have the time to receive the support, "*A couple of people have dropped out because they said they* *sometimes found it annoying to stop what they were doing and answer the phone when their lives are so busy anyway".*

4.3. Matching carers to volunteers

Two managers indicated matching does not take place between carers and volunteers prior to the first visit. Of the remaining seven, five argued that matching is important, vital or essential, "*...this is really important. There is an initial assessment and carers and volunteers are matched on having similar interests and similar outlooks on life*" and "*It is of prime importance to match the volunteer to the carer*". A number of different reasons for matching were highlighted, including being able to build trust, help form links and matching on people's personalities and requirements, " *I see this as vitally important as some carers are quite content with a good gossip while others will need someone who is willing to listen while they pour their heart out*".

Five managers emphasised that carers will often ask for a volunteer of the same gender, "*some carers want to speak to volunteers of the same gender only. It's quite common for females to request females only*" and "females tend to want female befrienders". Other characteristics on which matching occurs included age, race, ethnicity, hobbies and work history.

It is not apparent if the use of matching is based on any background knowledge or theory, with two managers and volunteer coordinators going with their experience in knowing what works well, " *There is no theory just a gut feeling after many years of working with volunteers about what relationships will work and what won't*" and " *There is no theory behind it, I just have a feeling who will go well together...who is good together, it naturally happened.*"

Acknowledgements

This survey was made possible thanks to the befriending, mentoring and peer support scheme managers and volunteer coordinators who kindly gave up their time to participate.

Further information

Further information can be obtained by contacting Raymond Smith on (020) 8266 6193 or email: k1163824@kingston.ac.uk.

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London, SW17 0RE

References

Department of Health. (2009). *Living Well with Dementia: A National Dementia Strategy*. London: Crown.

Appendix 14: Information letter for service managers

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
Cranmer Terrace
London SW17 0RE

www.healthcare.ac.uk

Dear (name of manager)

Project title: The impact of mentoring schemes on carers of people with dementia and on volunteer mentors

Who am I?

My name is Raymond Smith and I am a PhD student from the Faculty of Health and Social Care Sciences, St Georges, University of London and Kingston University. I am working on a project investigating befriending/mentoring/peer support schemes [delete as appropriate] for carers of people with dementia and the volunteers who deliver the intervention.

What is the study about?

This study is building upon previous research into befriending/mentoring/peer support schemes [delete as appropriate] schemes for carers. In particular, this study is focusing on the impact mentoring has on carers of people with dementia and on volunteers. There is a lack of research in this area and it is hoped this will provide new information about the effectiveness of mentoring and how mentoring works.

Why are you being asked to take part?

We are asking for your help to identify carers of people with dementia and volunteers in your service who may like to participate. In order to be eligible to participate, the carers and volunteers need to be new to the service and not yet have taken part in delivering or receiving befriending/mentoring/peer support [delete as appropriate]. If you decide you would like to assist, you will be sent pre-stamped envelopes with invitation letters for carers and volunteers and asked to send these to people new to the service.

What is involved for carers and volunteers?

Carers and volunteers who agree to take part will be asked to fill in three questionnaires at three time points over six months. This will take place in their own home or another place convenient to them. After six months, they may be asked to participate in a one-to-one interview which will explore their views and experiences of mentoring. Interviews are expected to take approximately 30-40 minutes per participant.

Confidentiality
Any information provided by the carers and volunteers will be kept anonymous and confidential. In reporting the project, the reader will not be able to identify who the respondent was or which service is being referred to. However, should information be shared which indicates a vulnerable adult is being harmed, I have a duty of care to share this information with local authority safeguarding teams.

What if I have any questions about the study?
Please contact me on the phone number or email address below and I would be happy to discuss any questions or concerns you may have. If you would prefer to talk to my PhD supervisor Dr Nan Greenwood, please contact her on the phone number or email address below.

What happens next?
I have included a stamped addressed envelope and a reply for you. This sheet asks for you to indicate whether or not you would like to take part and there is space for you to write any comments. Alternatively you can contact me by email or telephone. I will follow this letter up with a phone call in one to two weeks to see if you would like to take part if I do not hear from you in the meantime.
Those services who take part will be offered a detailed feedback of the findings.
I look forward to hearing from you.

Yours sincerely

Raymond Smith
Faculty of Health and Social Care Sciences
Second Floor Grosvenor Wing
St George's, University of London
Cranmer Terrace
London. SW17 0RE
Phone: (020) 8266 6193
Raymond Smith email: k1163824@kingston.ac.uk

Supervisor: Dr Nan Greenwood
Phone: Tel 020 8266 6208
Email: N.Greenwood@sgul.kingston.ac.uk

Appendix 15: Return participation form for service managers

Title: The impact of mentoring schemes on carers of people with dementia and on volunteer mentors.

I am interested in taking part and would like you to contact me with more information

Name:

Telephone number:

Best time to call:

Thank you, I will be in touch shortly. Please send the form back with the stamped addressed envelope provided.

Appendix 16: Information letter for potential carer participants

Kingston University London
St George's University of London

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
Cranmer Terrace
London SW17 0RE

www.healthcare.ac.uk

Title: The impact of mentoring schemes on carers of people with dementia and on volunteer mentors.

Participant information sheet

You are being invited to take part in a research study about befriending/mentoring/peer support [delete as appropriate]. Before you take part, it is important you understand what the research is about and what may be involved. Please take some time to read the information below. You can contact me if you would like any further information.

Who am I?
My name is Raymond Smith and I am a PhD student from the Faculty of Health and Social Care Sciences, St Georges, University of London and Kingston University. I am working on a project investigating mentoring schemes for carers of people with dementia and the volunteers who deliver the intervention.

What is the study about?
This study is building upon previous research into befriending, mentoring and peer support schemes. In particular, this study is focusing on the effect mentoring has on carers of people with dementia and on volunteers. There is a lack of research in this area and it is hoped this will provide new information about the effectiveness of mentoring and how it works.

What will participation involve?
You have been invited to take part because you recently joined a befriending/mentoring/peer support [delete as appropriate] service. If you agree to take part, I will ask to meet with you at your home or another place convenient for you. You will be asked to fill in three questionnaires at three time points over six months. These questionnaires are expected to take 30 minutes to fill in per visit. After six months, you may be asked if you would like to participate in an interview which will explore your views and experiences of mentoring. Potential participants will be selected for interview based on their scores from the questionnaires. This fourth and final visit is expected to last approximately 45 minutes and will be audio recorded unless you request otherwise.

Do I have to take part?
No, your participation is completely voluntary and, if you do decide to take part, you can withdraw from the study at any time without giving a reason. Your decision will not affect the befriending/mentoring/peer support [delete as appropriate] you are receiving in any way.

How long will the study last?
If you decide to take part, the study will take place over six months.

Where will the study take place?
At a place and time convenient to you, as long as your privacy can be maintained.

Are there any risks involved with participating?
You may find some topics discussed emotional and should you wish I will return on another occasion. Maintaining your privacy is a top priority and everything you say will remain completely confidential. However, should information be shared which indicates a vulnerable adult is being harmed, I have a duty of care to share this information with local authority safeguarding teams.

Are there any benefits involved with participating?
Whilst there may not be any direct benefits to you, the findings from this research will be valuable in terms of progressing knowledge in an area that is very under researched. You will be offered feedback of the findings.

What if I have any questions about the study?
I would be happy to discuss any questions or concerns you may have and you can contact me on the phone number or email address below. If you would prefer to talk to my PhD supervisor Dr Nan Greenwood, her contact details are below.

What happens next?
If you would like to take part please complete the return slip included or if you prefer you contact me on the details below.
I look forward to speaking with you.
Yours sincerely

Raymond Smith
Faculty of Health and Social Care Sciences
Room 1, Second Floor Grosvenor Wing
St George's, University of London
Cranmer Terrace
London. SW17 0RE
Phone: (020) 8266 6193
Raymond Smith email: k1163824@kingston.ac.uk

Primary supervisor: Dr Nan Greenwood

Phone: 020 8266 6208
Email: N.Greenwood@sgul.kingston.ac.uk

Appendix 17: Questionnaire collecting carer demographic details

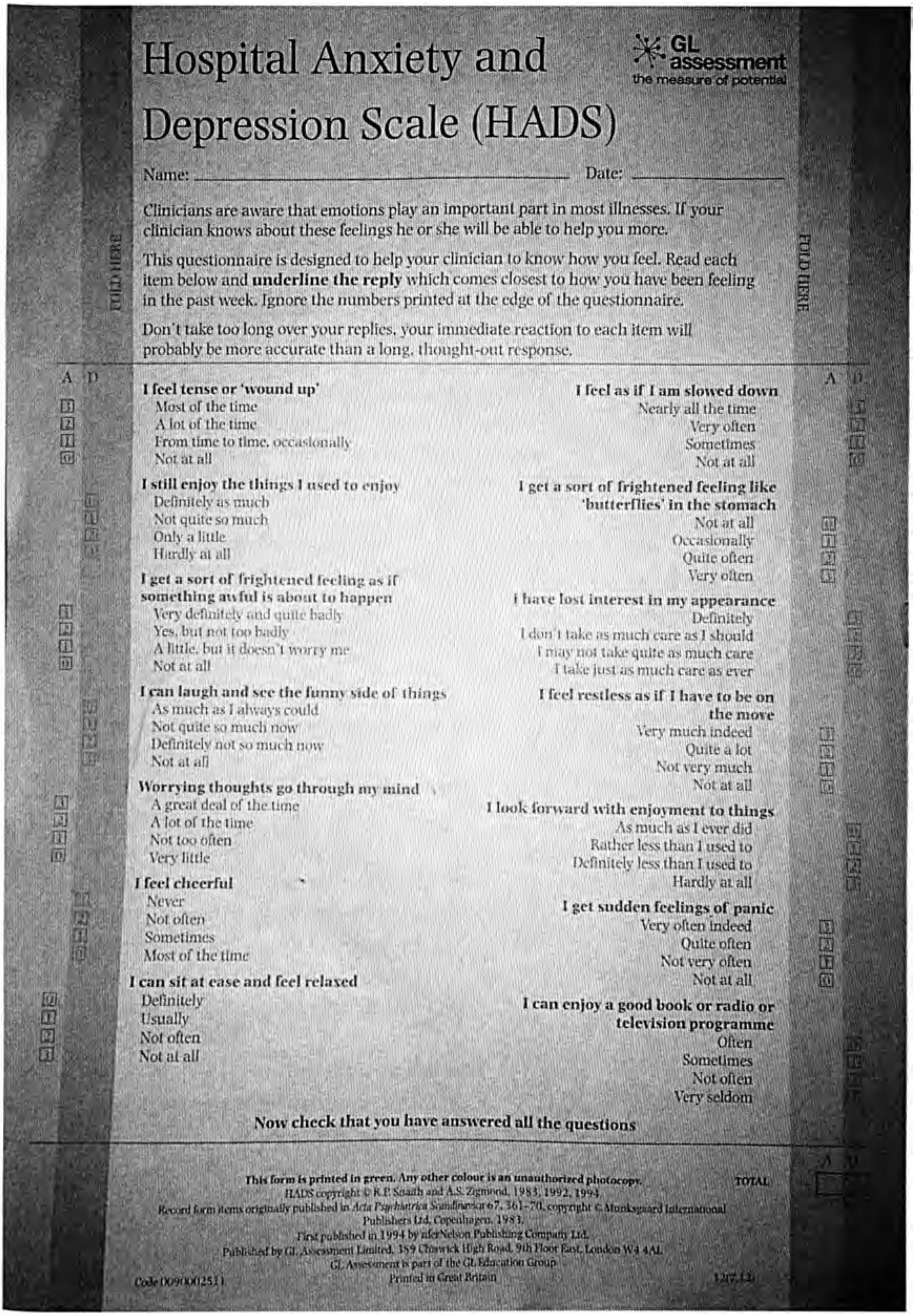
To maintain your privacy, all participants are given a code. This allows identification without the need for personal details. Please do not write your name, date of birth or address on this form.

Participant code (   )

Please fill in the table below fully as possible.

Age	
Gender	
Marital status	
How long have you been a carer? (in months or years – please specify)	
How are you related to the person with dementia?	
If known, what type of dementia does the person you are caring for have? (e.g. Alzheimer's disease)	
Do you receive any other type of support, e.g. Admiral Nurse, Dementia Adviser, Good Neighbour Scheme, attending support groups (including Dementia Cafes, sing-a-longs, etc.), Others (please specify)	

Appendix 18: Hospital Anxiety and Depression Scale



Hospital Anxiety and Depression Scale (HADS)

Name: ______________________ Date: __________

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A	D	
		I feel tense or 'wound up'
3		Most of the time
2		A lot of the time
1		From time to time, occasionally
0		Not at all
		I still enjoy the things I used to enjoy
	0	Definitely as much
	1	Not quite so much
	2	Only a little
	3	Hardly at all
		I get a sort of frightened feeling as if something awful is about to happen
3		Very definitely and quite badly
2		Yes, but not too badly
1		A little, but it doesn't worry me
0		Not at all
		I can laugh and see the funny side of things
	0	As much as I always could
	1	Not quite so much now
	2	Definitely not so much now
	3	Not at all
		Worrying thoughts go through my mind
3		A great deal of the time
2		A lot of the time
1		Not too often
0		Very little
		I feel cheerful
	3	Never
	2	Not often
	1	Sometimes
	0	Most of the time
		I can sit at ease and feel relaxed
0		Definitely
1		Usually
2		Not often
3		Not at all

	A	D
I feel as if I am slowed down		
Nearly all the time		3
Very often		2
Sometimes		1
Not at all		0
I get a sort of frightened feeling like 'butterflies' in the stomach		
Not at all	0	
Occasionally	1	
Quite often	2	
Very often	3	
I have lost interest in my appearance		
Definitely		3
I don't take as much care as I should		2
I may not take quite as much care		1
I take just as much care as ever		0
I feel restless as if I have to be on the move		
Very much indeed	3	
Quite a lot	2	
Not very much	1	
Not at all	0	
I look forward with enjoyment to things		
As much as I ever did		0
Rather less than I used to		1
Definitely less than I used to		2
Hardly at all		3
I get sudden feelings of panic		
Very often indeed	3	
Quite often	2	
Not very often	1	
Not at all	0	
I can enjoy a good book or radio or television programme		
Often		0
Sometimes		1
Not often		2
Very seldom		3

Now check that you have answered all the questions

This form is printed in green. Any other colour is an unauthorized photocopy. **TOTAL** A D

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Appendix 19: Multidimentional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

Appendix 20: UCLA Loneliness Scale (version 3)

Instructions: The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by placing a check in the space provided. Here is an example: How often do you feel happy? If you never felt happy, you would check "never"; if you always feel happy, you would check "always."

	NEVER 1	RARELY 2	SOMETIMES 3	ALWAYS 4
*1. How often do you feel that you are "in tune" with the people around you?				
2. How often do you feel that you lack companionship?				
3. How often do you feel that there is no one you can turn to?				
4. How often do you feel alone?				
*5. How often do you feel part of a group of friends?				
*6. How often do you feel that you have a lot in common with the people around you?				
7. How often do you feel that you are no longer close to anyone?				
8. How often do you feel that your interests and ideas are not shared by those around you?				
*9. How often do you feel outgoing and friendly?				
*10. How often do you feel close to people?				
11. How often do you feel left out?				
12. How often do you feel that your relationships with others are not meaningful?				
13. How often do you feel that no one really knows you well?				
14. How often do you feel isolated from others?				
*15. How often do you feel you can find companionship when you want it?				
*16. How often do you feel that there are people who really understand you?				
17. How often do you feel shy?				
18. How often do you feel that people are around you but not with you?				
*19. How often do you feel that there are people you can talk to?				
*20. How often do you feel that there are people you can turn to?				

Scoring: Items that are asterisked should be reversed (i.e., 1 4, 2 3, 3 2, 4 1), and the scores for each item then summed together. Higher scores indicate greater degrees of loneliness. From Russell DW. UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure. *J Pers Assess* 66:20-40, 1996.

Appendix 21: Topic guide for carers

Experience of the carers

Can you tell me how you heard about the befriending/peer support scheme?
Why did you choose to accept befriending/peer support?
Can you tell me what a typical befriending/peer support session may involve?

Impact on carers

Can you tell me what impact befriending/peer support has had on you?
Can you tell me about any positive aspects of befriending/peer support? If any.
Can you tell me about any negative aspects of befriending/peer support? If any.
Some research suggests carers have improved mood whilst receiving befriending/ peer support. Would you agree with this or not? Why?
Have you noticed any changes in yourself over time since you started to receive befriending/peer support?
Do you think there are any benefits or downsides to the person you're caring for?

About the volunteers

What personal qualities do you think a befriender/peer supporter needs?
What skills do you think a befriender/peer supporter needs?

Impact on volunteers

In your opinion what impact does befriending/peer support have on befrienders/peer supporters?
Some research suggests that improved mood can result from volunteering. Do you think this could be the case with the person befriending/peer supporting you?
Has a befriender/peer supporter mentioned any positives about their role?
Has a befriender/peer supporter mentioned any negatives about their role?

Experiential similarity

Do you think it is important that a befriender/peer supporter has previous caring experience, or not? Why?
Do you know if your befriender/peer supporter has prior unpaid caring experience?
    If yes, in what ways do you think it has had an impact on your befriending/peer support relationship?
    If no, in what ways do you think the volunteer having prior caring experience may have helped?

Matching

Do you know if the scheme you receive befriending/peer support from have a matching procedure for befrienders/peer supporters and carers?
    If yes, do you know in what ways are you matched?
    If yes, were you matched with the volunteer before befriending/peer support began?

Do you think matching is important for developing a strong befriending/peer support relationship volunteers, or not?

Anything else?

Is there anything else that we haven't covered which you would like to mention or talk about?

Appendix 22: Topic guide for volunteers

Experiences of the volunteers

How did you hear about the befriending/peer support service?
What made you decide to become a befriender/peer supporter?
What do you think befriending/peer support aims to achieve?
Can you tell me what a befriending/ peer session usually involves?
Were you given training before you started befriending/peer supporting? If so, what did it involve?
Are you given supervision on an ongoing basis? If so, what did it involve?
If yes, do you think it helps you in providing a better experience for the person being befriended?
If no, would you find it useful if offered?
In your experience what makes for a good befriending/peer support relationship?
In your experience what makes for a long lasting befriending/peer support relationship?
What personal qualities do you think you need to be a good befriender/ peer supporter?
What skills do you think you need to be a good befriender/ peer supporter?

Impact on volunteers

Has befriending/peer support had an impact on you? If so, how?
Are there any positive aspects of being a befriender/peer supporter? If so, what are they?
Are there any negative aspects of befriending/peer support? If so what are they?

Experiential similarity

Do you have prior unpaid caring experience?
If yes, in what ways do you think it has helped in being able to befriend/peer support carers?
If yes, have carers suggested to you that they find your prior caring experience important?
If no, do you think having prior experience may have helped you support the carers, or not?

Matching

Does the scheme you volunteer for have a matching procedure for befrienders/ peer supporters and carers?
    If yes, in what ways are you matched?
If yes, are you matched with the carers before befriending/peer support begins?
Do you think matching is important for developing a strong befriending/peer support relationship with carers, or not?

Experiences of the carers

In your experience, why do carers accept befriending/peer support?
In your experience, in what ways does befriending/peer support impact on carers?
Have carers mentioned any positive aspects of being befriended/peer supported?
Have they mentioned any negative aspects of being befriended/peer supported?
Have you seen any positive or negative changes in the carers over time?
Some research suggests that mentoring can improve mood for carers. In your experience do you think this is correct? If yes, why?

Do you think there are any benefits or downsides to the person being cared for?

Anything else?

Is there anything else that we haven't covered which you would like to mention or talk about?

Appendix 23: Development of framework for carer participants

Framework (carers) developed after data familiarisation (03/06/2014)

Themes	Subthemes
Not alone	• Someone there for the carer • Reduces social isolation • A sense of being connected to society • Carers have someone to talk/chat to – not just talking about caring or dementia • Someone to talk to as problems arise • Carers now realise others are going through similar situations/normalising/putting things in perspective
Safe environment to share	• Non-judgemental volunteer • Talk about a variety of topics • Can share problems that are too difficult to share with family • Carers can discuss difficult or 'taboo' topics • Offload thoughts and feelings – being heard • Can discuss more personal topics than in a support group
Advice and information	• Learning new ways to deal with behaviours • Networked into other services • Increased confidence in own caring abilities • Learning and passing on information • Practical advice about benefit entitlements
Emotional support	• Carers have their feelings validated • Emotional boost/having their emotions and feelings taken care of • Empowering carers to seek out other forms of support • Helps carers get through difficult situations • Enabled the carers to carry on caring • Increase confidence in caring abilities • Reduces stress • Something for carers to look forward to
Other (carers)	• Improved relationship with person being cared for • An assumption by carers volunteer mentoring will be helpful • Importance of more personalised local services • Importance of recognising individual differences of carers • Flexibility over when and how support is given (this can often change as time goes on)

Experiential similarity	• Experiential similarity is very important • Volunteer has an understanding of the situation • Volunteer has had 'real' experience of caring for a person with dementia • Volunteers have 'insider knowledge'
Volunteer characteristics	• Good listeners • Non-judgemental • Kind and sympathetic • Patience and tolerance • Importance of and getting on well common interests • Positive and friendly nature of volunteer • Importance of volunteer having a sense of humour and positivity
Benefits and negatives for volunteers	• Possibly stressful for volunteers • Sense of purpose and enjoyment in helping others • Satisfaction from helping others • Keeps volunteers active • Volunteers get a lot in return • Could be it brings up painful memories
Other (volunteers)	• Importance of personalised support which volunteer mentor can give • Having a laugh with the volunteer can boost mood of carers
Mutually beneficial for carers and volunteers	• Sharing experiences and feelings between carers and volunteers • Carers and volunteers take care of each other's emotional needs • Volunteers get to share their worries mutual benefit • Taking care of each other

Framework (carers) developed after indexing (16/06/2014)

Themes	**Subthemes**
Being heard	• Talk about a variety of difficult topics • Personalised support • Carers look forward to the support
Safe environment	• Volunteers and carers can share feelings • Emotional support • Offload thoughts and feelings • Get through difficult situations

Experiential similarity	• Volunteer characteristics (former carer of a person with dementia, non-judgemental, empathic, sympathetic, good listener, patient, cheerful and positive)
Not alone	• Advice and information • Networked into other support services
Mutually beneficial for volunteers	• Volunteer well-being (sense of purpose, keeping active, giving something back, enjoyment in successfully helping others)

Final framework (carers) developed after charting (28/06/2014)

Themes	**Subthemes**
Aspects of volunteer mentoring carers value and enable the development of successful relationships	• Experiential similarity • Volunteer characteristics
Carers feel listened to	• Safe environment • Sustaining emotions • Getting through difficult situations
Someone there just for the carer	• Advice and information • Personalised support • Carers look forward to the support (enjoyment) • Reduced social isolation
Reciprocity of support between carer and volunteer	• Sharing between carer and volunteer • Volunteer well-being • Volunteer enjoyment

Appendix 24: Development of framework for volunteer mentor participants

Framework (volunteers) developed after data familiarisation (19-07-2014)

Themes	**Subthemes**
Benefits for volunteers.	• Retrain for a new career • Training and experience • Keeping active • Pass on knowledge • Wanting to help others • Received volunteer mentoring when caring and now want to help • Sharing between volunteer and carer • Enjoyment in helping others • Satisfaction in helping others/rewarding • Making new friends • Social inclusion improvements • Feel part of something • Giving something back • Making a difference • Mood improvements • Self-esteem
Perceived benefits for carers	• Emotional support • Emotional support • Offload thoughts and feelings • Being listened to/just being there • Mental health/lessens stress • Reduced Isolation and loneliness • Social inclusion – regular support • Physical activity • Sport and activities • Networked into other services • Advice • Older and frail more likely to be isolated and need support • Free support (carers on low income in particular benefit/attracted to it) • Opportunity to talk to someone other than health professionals • Carers can confide in the volunteers – often can't talk to family • More confident and assertive/self-esteem
Perceived benefits for the person with dementia	• Carer more patient with them • Feels less irritated with person with dementia • Carer is less stressed and more positive so can do a better 'job' • Can stay at home longer

Potential negatives for carers	• Not appropriate for everyone • Volunteers without experiential similarity suggest carers might have an improved experience if they did have it • Stigma attached to being a 'befriender'
Potential negatives for volunteers	• Hearing about someone else's problems can be difficult • Stressful • Privacy issues – disclosing personal information
What makes for strong volunteer mentoring relationship?	• Common interests • Experiential similarity • Matching/manager introduces volunteer to carer • Importance of keeping boundaries and distance • Doing things together they both like • Trust • Carers look forward to the support • Flexibility
Personal qualities and skills needed by	• Caring personality • Cheerful/positive attitude • Listening skills • Sense of humour • Reliability • Patience
Training and supervision	• Would appreciate training/supervision if offered • Volunteers without prior experience place more emphasis on the need for training and supervision • Supervision is useful - can pass on problems

Framework (volunteers) developed after indexing (25/07/2014)

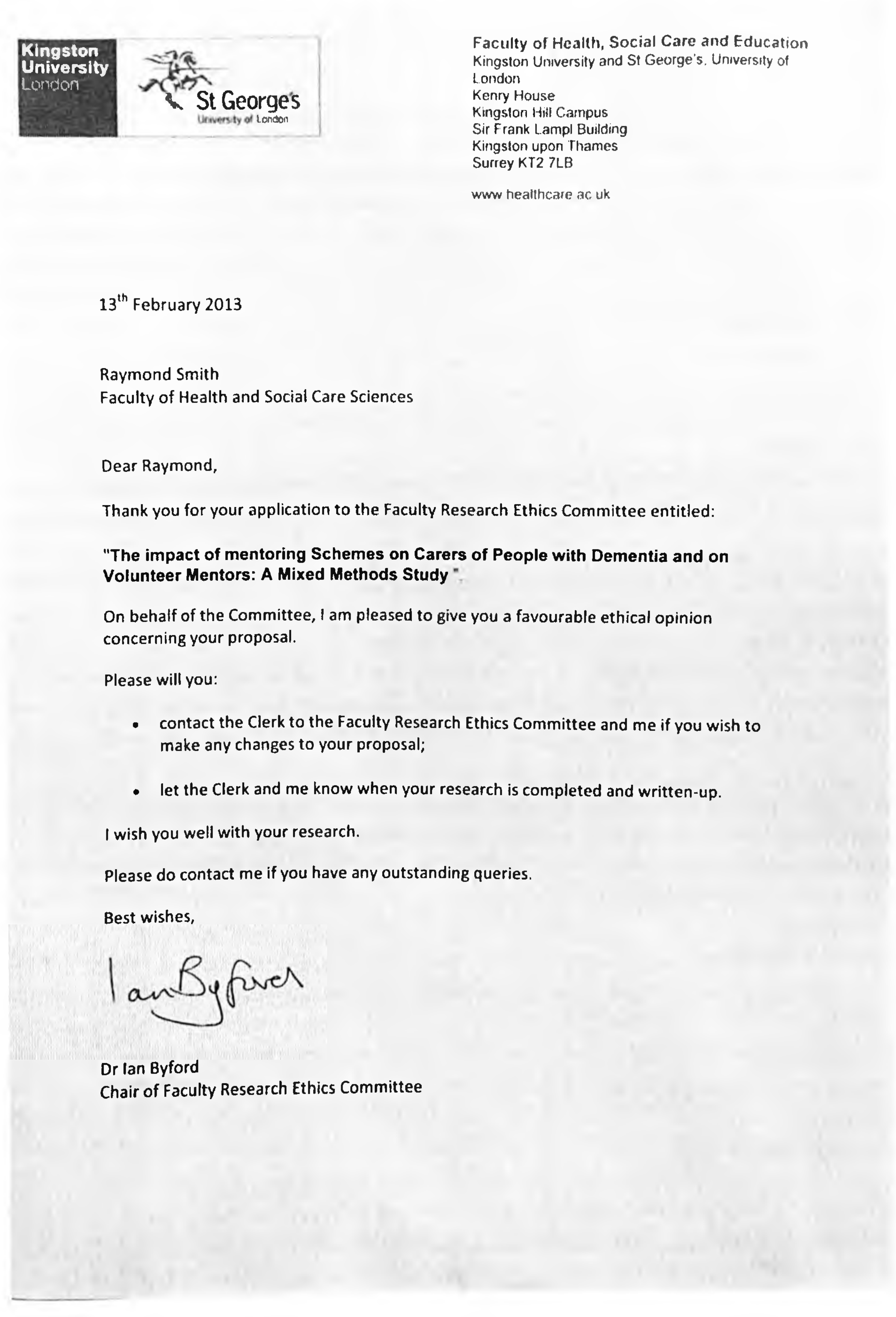
Themes	**Subthemes**
Developing a bond with carers	• Experiential similarity ○ Importance of former caring experience ○ Similarity on other aspects (personality and interests) ○ Training for those who do not have experiential similarity (half the volunteers did not have experiential similarity and highlighted its importance more than those who did) ○ Leads to trust and the formation of stronger bonds/connections • Volunteer characteristics

Making a difference	• Carers can confide in someone allowing: o Improved coping ability o Emotional support o Reduced social isolation o Potential positives for the person with dementia • Every day is different o Emotional benefits are short lived o Offloading negative emotions regularly o Increased coping ability o Empowerment
A sense of belonging	• Reciprocity of support/mutual benefits o Appreciation from carers for what they do o Self-esteem o Mental and physical improvements o Social gains • Role o Sense of purpose o Gain experience for a new career o Help with 'moving on' from being a carer

Final framework (volunteers) developed after charting (11/08/2014)

Themes	**Subthemes**
Developing a bond	• Experiential similarity • Volunteer characteristics • Common interests
Someone for carers to talk to	• Carers feel listened to • Emotional support • Social inclusion • Coping ability
Helping themselves through helping others	• Mutual benefits • Making a difference • Burden on volunteers • Part of a bigger picture

Appendix 25: Phase Two research protocol and ethics approval



Faculty of Health, Social Care and Education
Kingston University and St George's, University of London
Kenry House
Kingston Hill Campus
Sir Frank Lampl Building
Kingston upon Thames
Surrey KT2 7LB

www healthcare ac uk

13th February 2013

Raymond Smith
Faculty of Health and Social Care Sciences

Dear Raymond,

Thank you for your application to the Faculty Research Ethics Committee entitled:

"The impact of mentoring Schemes on Carers of People with Dementia and on Volunteer Mentors: A Mixed Methods Study ".

On behalf of the Committee, I am pleased to give you a favourable ethical opinion concerning your proposal.

Please will you:

- contact the Clerk to the Faculty Research Ethics Committee and me if you wish to make any changes to your proposal;
- let the Clerk and me know when your research is completed and written-up.

I wish you well with your research.

Please do contact me if you have any outstanding queries.

Best wishes,

Ian Byford

Dr Ian Byford
Chair of Faculty Research Ethics Committee

APPLICATION FORM FOR ETHICAL REVIEW RE4 FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

Faculty reference

SECTION A

Is this an application for a ‘block release agreement’:

Yes		No X	

If *yes*, please specify the name of the group/cohort and note who will be responsible for ethical oversight of projects in this area (the block release holder); this will usually be the module leader, supervisor or head of subject. This RE4 form should present a project *typical* to this group/cohort.

Project title:

The impact of mentoring Schemes on Carers of People with Dementia and on Volunteer Mentors: A Mixed Methods Study

Name of the lead applicant:

Name (Title / first name / surname):	Mr Raymond Smith
Position held:	PhD student
Department/School/Faculty:	Faculty of Health and Social Care Sciences
Telephone:	(020) 8266 6193
Email address:	K1163824@kingston.ac.uk

Name of co-applicants:

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	
Telephone:	
Email address:	

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	
Telephone:	
Email address:	

Name (Title / first name / surname):	
Position held:	
Department/School/Faculty:	
Telephone:	

Email address:	

Is the project: Student research	Yes	X	No	
KU Staff research	Yes		No	
Research on KU premises	Yes		No	

If it is STUDENT research:

Course title	PhD
Supervisor/DoS	Dr Nan Greenwood

SECTION B ***(Complete this section if another ethics committee has already granted approval for the project. Otherwise, proceed to Section C)***

Committee that granted approval	
Date of approval	

Please attach evidence that the project has been fully approved (usually an approval letter). The original application should be retained on file in the Faculty for inspection where necessary. The Faculty Research Ethics Committee (FREC) may require further information or clarification from you and you should not embark on the project until you receive notification from the FREC that recognition of the approval has been granted. You should proceed directly to Section D of this form and submit this as a fast-track application.

SECTION C

Provide a brief project description (max. 150 words). This should be written for a lay audience

This mixed methods study explores the impact of mentoring (befriending, mentoring and peer support) schemes, on carers of people with dementia and on volunteer mentors. Data collection is expected to last approximately eleven months (from January 2013) and has a quantitative and a qualitative phase. The quantitative phase will involve carers and volunteers completing three questionnaires investigating depression, loneliness and social inclusion (appendix 1, 2 and 3) at three time points (baseline, three months and six months).The qualitative phase will involve in-depth one to one interviews after six months, with a sample of carers and volunteers who scored highest and lowest on the quantitative scales. These interviews will explore carers' and volunteers' feelings, attitudes and perceptions of mentoring. Quantitative data will be recorded in the Statistical Package for the Social Sciences version 17 (SPSS). For the quantitative phase, power and sample size calculations will be conducted after consultation with a statistician. Qualitative data will be transcribed to enable analysis using NVivo 10. For the qualitative phase, approximately 20 carers and 20 volunteers will be interviewed depending on the initial thematic analyses.

Estimate duration of the project (months)	11 months (January 2013 – November 2013)
State the source of funding	

Is it collaborative research?

Yes		No	X

If YES, name of the collaborator institutions:

1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	

Briefly describe the procedures to be used which involve human participants

Initially, managers of schemes will be approached with the sending of an information letter (appendix 4). The managers will be asked to contact carers and volunteers, who are new to the service, to ascertain whether they would like to take part in the study and would like to receive an invitation letter (appendix 5). Those volunteers and carers who return the attached reply slip (with the included stamped addressed envelope) to the researcher will be followed up with a telephone call to arrange a suitable time and date for the initial data collection to commence. Prior to data collection potential participants will be asked to read and, if they are happy to continue to sign the consent form (appendix 6). This will indicate they understand what the study is about and that two follow up visits will be required. Also, they will be informed that their participation is voluntary, they can withdraw at any time, their responses are confidential and that interviews will be anonymised and identified by code only. At this point if the participant declines to take part, they will be thanked for their time and their details will be destroyed. Qualitative interviews will be digitally recorded and participants will be asked to indicate on the consent form (appendix 6) that they agree to this. If participants do not wish to be recorded, the researcher will take notes by hand. Should participants become distressed during the interview, the researcher will ask if they would like to stop and arrange another time to continue if they so wish.

Summarise the data sources to be used in the project

Data will be collected through the administration of three self report questionnaires covering mental well-being, social inclusion and loneliness (which are repeated at three time points to measure change) and in-depth interviews (after the quantitative phase). The one to one interviews will explore participants' thoughts and feelings towards mentoring, and its perceived impact. All data collected will be anonymised and coded to ensure confidentiality and the audio recordings will be transcribed on to a password protected University computer.

Storage, access and disposal of data

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Quantitative data, such as demographic details of volunteers and carers and responses to the scales, will be recorded by hand (whilst interviewing participants), and then entered into an electronic database on a University password protected computer. Qualitative interviews will be transcribed for later analysis and stored on the same password protected University computer. The audio recordings will be destroyed on the same day they have been transcribed. Each participant will be assigned an identification number in order to maintain confidentiality and these will be stored in a separate file on the same computer.

Further, all hard copies of transcripts and scales will be stored in a locked cabinet which only the researcher has access to. Once analysed, the hard copies of transcripts and responses to scales will be destroyed. The electronic data will then be retained on a password protected University computer until research is complete, which is anticipated to be October 2014. At this time it will be destroyed.

before being destroyed.

Risk Assessment Questionnaire: Does the proposed research involve any of the following?

		YES	N
0.	The use of human biological material?		X
1.	Children or young people under 18 years of age?		X
1.a	If YES, have you complied with the requirements of the CRB?		
2.	People with an intellectual or mental impairment, temporary or permanent?		X
3.	People highly dependent on medical care, e.g., emergency care, intensive care, neonatal intensive care, terminally ill, or unconscious?		X
4.	Prisoners, illegal immigrants or financially destitute?		X
5.	Women who are known to be pregnant?		X
6.	Will people from a specific ethnic, cultural or indigenous group be targeted in the proposed research, or is there potential that they may be targeted?		X
7.	Assisted reproductive technology?		X
8.	Human genetic research?		X
9.	Epidemiology research?		X
10.	Stem cell research?		X
11.	Use of environmentally toxic chemicals?		X
12.	Use of ionizing radiation?		X
13.	Ingestion of potentially harmful or harmful dose of foods, fluids or drugs?		X
14.	Contravention of social/cultural boundaries?		X
15.	Involves use of data without prior consent?		X
16.	Involves bodily contact?		X
17.	Compromising professional boundaries between participants and researchers?		X
18.	Deception of participants, concealment or covert observation?		X
19.	Will this research significantly affect the health* outcomes or health services of subjects or communities?		X
20.	Is there a significant risk of enduring physical and/or psychological harm/distress to participants?		X

21. Does your research raise any issues of personal safety for you or other researchers involved? (especially if taking place outside working hours or off KU premises)

22. Will the research be conducted without written informed consent being obtained from the participants?

23. Will financial/in kind payments (other than reasonable expenses and compensation for time) be offered to participants? (Indicate in the proposal how much and on what basis)

24. Is there a potential danger to participants in case of accidental unauthorised access to data?

[**Note** *health is defined as not just the physical well-being of the individual but also the social, emotional and cultural well-being of the whole community].

<u>SECTION D</u> *(To be signed by all applicants)*

Declaration to be signed by the applicant(s) and the supervisor (in the case of a student):

- I confirm that the research will be undertaken in accordance with the Kingston University *Guidance and procedures for undertaking research involving human participants.*

- I will undertake to report formally to the relevant Faculty Research Ethics Committee for continuing review approval where required.

- I shall ensure that any changes in approved research protocols or membership of the research team are reported promptly for approval by the relevant Faculty Research Ethics Committee.

- I shall ensure that the research study complies with the law and University policy on Health and Safety.

- I confirm that the research study is compliant with the requirements of the Criminal Records Bureau where applicable.

- I am satisfied that the research study is compliant with the Data Protection Act 1998, and that necessary arrangements have been, or will be made with regard to the storage and processing of participants' personal information and generally, to ensure confidentiality of such data supplied and generated in the course of the research.
  (Further advice may be sought from the Data Protection Officer, University Secretary's Office)

- I shall ensure that the research is undertaken in accordance with the University's Single Equality Scheme.

- I will ensure that all adverse or unforeseen problems arising from the research project are reported immediately to the Chair of the relevant Faculty Research

Ethics Committee.

- I will undertake to provide notification when the study is complete and if it fails to start or is abandoned;

- (For supervisors, *if the applicant is a student)* I have met and advised the student on the ethical aspects of the study design, and am satisfied that it complies with the current professional (*where relevant),* departmental and University guidelines. I accept responsibility for the conduct of this research and the maintenance of any consent documents as required by this Committee.

- I understand that failure to provide accurate information can invalidate ethical approval.

Is this an application for fast-track ethical approval?

Yes	X	**No**	

Please sign and date	*Signature*	*Date*
Lead applicant		10/12/12
Co-applicant		
Co-applicant		
Co-applicant		
Supervisor		10/12/12

NOTE

If this is a block release application and/or you have answered YES to any of the questions in the Risk Assessment, you must complete a full application for ethical approval and provide the information outlined in the checklist below. Your project proposal should show that there are adequate controls in place to address the issues raised in your Risk Assessment.

If you have answered NO to all of the questions in the Risk Assessment you may submit the form to your Faculty Ethics Administrator as a fast-track application. You must append your participant information sheet. The Faculty Research Ethics Committee (FREC) may require further information or clarification from you and you should not embark on the project until you receive notification from your Faculty that recognition of the approval has been granted.

CHECKLIST ***(Where a full application for ethical approval is required)***

Please complete the checklist and attach it to your full application for ethical approval:

Before submitting this application, please check that you have done the following: *(N/A = not applicable)*	**Applicant**			*Committee use only*		
	Yes	**No**	**N/A**	**Yes**	**No**	**N/A**
All questions have been answered	**X**					
All applicants have signed the application form	**X**					
The research proposal is attached	**X**					
Participant Information Sheets are attached	**X**					
All letters, advertisements, posters or other recruitment material to be used are attached	**X**					
All surveys, questionnaires, interview/focus group schedules, data sheets, etc, to be used in collecting data are attached	**X**					
Reference list attached, where applicable	**X**					

The impact of mentoring Schemes on Carers of People with Dementia and on Volunteer Mentors: A Mixed Methods Study

This research protocol is for a study exploring the impact and experiences of mentoring schemes on carers of people with dementia, and the volunteers who deliver the interventions.

Background

Carers

It is estimated that 670,000 people in the UK are the primary carers for a person with dementia (Alzheimer's Society, 2012). For many carers, their role impacts upon their mental well-being, physical health, relationships, finances, social inclusion and increases loneliness (Carers UK, 2004; Leggett et al. 2010). In particular, carers of people with dementia are more likely than carers of people with other illnesses and non-carers to suffer from loneliness, social exclusion and physical and mental health issues, due to the unique stressors of this caring role (Beeson, 2003; Etters et al. 2008; Pinquart & Sorenson, 2003).

Volunteers

In the year 2009-2010, it was shown by the Citizenship Survey (Department for Communities and Local Government, 2010) that 40 per cent of adults in England had volunteered formally at least once in the previous 12 months. Numerous reported benefits for people who choose to volunteer have been highlighted, including improvements in mental and physical health, increased social inclusion and reduced loneliness (Musick & Wilson, 2003; Omoto & Snyder, 1993). Whilst there is research highlighting the positive impact of volunteering in general (Casiday et al. 2008), evidence for this positive impact for those providing interventions for carers of people with dementia is lacking.

Mentoring

One possible way of decreasing loneliness, increasing social inclusion and improving mental health in carers and volunteers is by engaging in mentoring schemes (Casiday et al. 2008; Cattan et al. 2011). Whilst there is evidence to suggest one-to-one mentoring offers beneficial outcomes for carers in general (Mead et al. 2010), the evidence for the effectiveness for such support schemes for carers of people with dementia is unclear (Arksey, 2003; Charlesworth et al. 2008). Furthermore, a previous systematic review undertaken as part of this PhD (Smith, 2012) showed there is a lack of research exploring the impact on volunteer mentors, and there is a great deal of difference among how these schemes are currently operating.

Importance of this study

The lack of evidence for the effectiveness of mentoring for carers of people with dementia and the volunteers is of concern, given that government policy is promoting these schemes and they are likely to increase in number in the coming decade (Department of Health, 2009; p.5). This study will investigate the impact these schemes have and explore carers and volunteers' experiences of using them.

Research questions and aims

The research questions are:

1. What is the evidence for the impact of mentoring schemes for carers and volunteers?
2. What do the processes of mentoring involve and what types of relationships do carers and volunteers form?

Primary aims:

1. To investigate the impact mentoring is having on carer and volunteer well-being (quantitative scales).
2. To explore to what extent mentoring is beneficial for carers and volunteers (qualitative interviews)

Secondary aims:

1. To improve understanding of the processes underlying mentoring.
2. To investigate the differences between the different types of mentoring schemes (befriending, mentoring, peer support).
3. To improve understanding of the relationships which are formed between carers and volunteers.
4. To investigate at what point in the caring role mentoring is most likely to be acceptable and effective, e.g. to carers of someone with mild dementia or to carers of someone in the later stages of dementia (how long the person with dementia has had the illness will be collected with other demographics during the initial visit).
5. To investigate if mentoring impacts on how often carers use statutory service (e.g., is it likely to lead to a reduction in GP visits).

Methods

Study design

A sequential explanatory mixed methods design will be used (Creswell, 2009; Tashakkori & Teddlie, 1998). Data collection for carers will include three quantitative self-report scales and one-to-one qualitative interviews. The same three scales will be used with the volunteer mentors it will involve one-to-one qualitative interviews. The two phases are as follows:

Quantitative phase

This initial phase will be quantitative and will involve face-to-face data collection from carers and volunteers over six months. There will be three data collection points (baselines, three months and six months). It is important that data are collected from carers over at least a six month time period as previous research identified from the systematic review as part of this PhD research, showed that the benefits of befriending only started to become evident after this time point (Charlesworth et al. 2008). Whilst no evidence has been found indicating positive outcomes for volunteers in this population, previous research has highlighted depression, loneliness and social inclusion as key factors for improvements in other types of volunteers (Casiday et al. 2008; Musick & Wilson, 2003; Omoto & Snyder, 1993). Due to the lack of previous research and these factors also being key outcomes for carers, it was decided to use the same outcome measures for the volunteers.

The following scales will be used. Licenses for all scales will be purchased prior to use. Copies of the scales are available in the appendix.

1. Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) (Appendix 1).
2. UCLA Loneliness Scale (version 3), (Russell, 1996) (Appendix 2).
3. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al. 1988) (Appendix 3).

During the initial visit to participants, demographic data will be collected. This will include, for example, age (in years), gender, ethnicity, marital and occupational status. Further questions for carers will ask how long they have been caring for the person with dementia (in years and months) and when the person with dementia was diagnosed with the illness (if known). Volunteers will also be asked if they are former carers of a person with dementia.

Qualitative phase

Carers and volunteers will be interviewed in-depth at six months after the quantitative data collection is complete. This will be face-to-face and take place in the participant's home. Participants will be selected for interview depending on scores showing the most and least change on the quantitative scales. This will enable the integration of quantitative and qualitative findings.

Draft topic guides for in-depth one to one interview with sampled carers

1. Was mentoring as you expected?
2. What did mentoring give you?
3. What was your relationship like with the volunteer?
4. What, if any, were the positives and downsides to mentoring?
5. Are you more or less likely now to use statutory services since receiving mentoring?
6. Do you feel you have more confidence or ability with caring since being mentored?

Draft topic guides for one to one interviews with sampled volunteers

1. Why did you choose to become a mentor?
2. How did you find the mentoring experience?
3. What, if anything, did you gain from mentoring?
4. What was your relationship like with the carer?
5. What, if any, were there the challenges you faced whilst mentoring and how did you overcome them?

Inclusion criteria

To be included, carers should be caring for a person with dementia and be new to the mentoring scheme. Volunteers should be delivering mentoring to carers of people with dementia and have a role described as either a befriender, mentor or peer supporter.

Exclusion criteria

Carers who are not caring for a person with dementia, are under 18 years old or pay to receive mentoring will be excluded. Volunteers who are paid to deliver mentoring or are under 18 years old will also be excluded.

Participant recruitment

Firstly, mentoring scheme managers will be contacted to explain the study and to see if they will be willing to assist in participant recruitment. This will be conducted in three ways:

1. In a previous study as part of this PhD, managers of mentoring services were contacted and asked to complete a survey. A number of the managers who took part indicated they would like to be considered for future research and will be sent the invitation letter (appendix 4) for this study.
2. Organisations not contacted as part of the survey study will be sent the invitation letter explaining the research.
3. I will approach organisations and ask to attend meetings the schemes holds in order to explain the study to scheme managers and potential participants.

Secondly, managers who agree to assist in participant recruitment will be sent pre-stamped envelopes containing invitation letters to send out to volunteers and carers who are new to the service (appendix 5). These information sheets will contain return forms with stamped addressed envelopes which carers and volunteers can send to the researcher indicating they would like to take part. The researcher will then contact the potential participant when these forms are received.

Sample sizes and power calculations

Due to the lack of research in this area, defining an adequate effect size to enable sample size calculations for the quantitative phase is challenging. Power calculations and sample sizes will be determined after consultation with a statistician.

For the qualitative phase to the research, it is expected that 40 participants will be interviewed 20 carers and 20 volunteers). However, fewer participants may be interviewed if data saturation is observed whilst conducting the data analysis (Parahoo, 1997).

Procedure

Carers and volunteers will be new to the mentoring service. Those volunteers and carers who indicate to the managers they do wish to take part (who will ask if it is ok to pass on their phone number to the researcher) will be followed up with a telephone call to arrange a suitable time and date for the initial data collection to commence. Prior to data collection participants will be asked to read and, if they are happy to continue, sign the consent form (appendix 6 and 7). This will indicate they understand what the study is about and that follow up visits may be required. Also, participants will be informed that their participation is voluntary, they can withdraw at any time, their responses are confidential and that interviews will be anonymised and identified by code only. At this point if the participant declines to take part, they will be thanked for their time and their details will be destroyed. Qualitative interviews will be digitally recorded and participants will indicate on the consent form (appendix 6) that they agree to this. If participants do not wish to be recorded, the researcher will take notes by hand.

Data Management

Quantitative data, such as demographic details of volunteers and carers and responses to the scales, will be recorded by hand (whilst interviewing participants), and then entered into an electronic database on a University password protected computer. Qualitative interviews will be transcribed using a Word document for later analysis and kept on the same password protected University computer. Participants will be asked if they would like to hear the recording before it is transcribed. Each participant will be assigned an identification number in order to maintain confidentiality.

Further, all hard copies of transcripts and scales will be stored in a locked cabinet which only the researcher has access to. Once analysed, the hard copies of transcripts and responses to scales will be destroyed. The electronic data will then be retained securely until the PhD research is complete, which is anticipated to be October 2014. At this time it will be destroyed.

Data analysis

The qualitative data gathered from interviews with carers and volunteers will be coded and analysed for themes (Auerbach & Silverstein, 2003) using the NVivo software package. Analysis of the qualitative data will start during the data collection phase. Quantitative data will be analysed using the Statistical Package for the Social Sciences (SPSS version 17) and the analysis conducted once all data collection is complete.

Ethical considerations

Ethical approval will be sought from the Kingston University Faculty Research Ethics Committee (FREC). The ethical considerations highlighted in this section were documented using the Economic and Social Research Council Framework for Research Ethics (ESRC, 2010) as a framework.

Participants

The participants in this study will be volunteers and carers of people with dementia who are new to mentoring schemes. They will be fully informed of the purpose of the study by being sent an invitation letter beforehand (Appendix 5). Before any data collection begins the purpose of the study, confirmation that their participation is voluntary and the participant's right to withdraw at any time will be repeated verbally. They will be informed that they are under no obligation to answer any of the questions of they do not wish to and do not have to give a reason for doing so. Participants will be told approximately how long interviews are expected to take and that two follow up visits will be necessary after three and six months.

Confidentiality

All participants will be informed that their responses to the questionnaires are confidential and will be kept in a locked cabinet on University premises. Only a number will be used which will enable the researcher to identify questionnaires from the same individuals. Identifying information (such as names, addresses other personal information) present in qualitative interviews will be deleted or masked with a blank space in the writing up of transcripts. Participants will be informed that no personal details will appear in future publications and that no information they provide will be made available to the mentoring service. The names, telephone numbers, addresses of participants and identification numbers will be stored in a separate file on a password protected University computer.

Participants will also be informed that should they share any information which indicates a vulnerable adult is being harmed, the researcher has a duty of care to share this information according to local safeguarding vulnerable adults procedures.

Informed consent

Informed consent will be obtained before both quantitative and qualitative data collection (appendix 6 and 7). Participants will not be paid for taking part in the study.

Right to withdraw

Participants will be informed prior to starting the interview that they can withdraw at any time without giving a reason and the information they have provided will be destroyed if they wish.

Potential problems

Anticipated problems which could be encountered when conducting the study are detailed below. Where possible, the measures to be taken to try and reduce the chance of such issues occurring have been identified and explained.

- Participants may talk about sensitive information about their caring role which could lead to feelings and expressions of sadness. If this occurs, they will be asked if they would like to stop the interview and, if appropriate, for the researcher to return on another occasion. It will also be suggested that they seek further support from the organisation they receive mentoring from.
- The questionnaires could also be upsetting for carers and volunteers if they see some of the questions as intrusive. It will be made clear before the participants start to fill in the questionnaires that they can stop at any time and do not have to continue if they wish. The researcher will take a list of telephone numbers of local services which can be given to participants if they indicate they would like further assistance.
- Should participants share any information which indicates a vulnerable adult is being harmed, this information will be passed on to the appropriate organisation. The participants will be informed of this before consenting to participation.
- In order to reduce risk to researcher safety, the Kingston University lone working

policy will be followed (Kingston University, 2012). A mobile phone will be carried at all times and at the end of each visit, a call or email will be made to a named person (Health and Safety Executive, 2009). Also, serviced providers will be asked if risk assessments have been carried out with carers before starting data collection.

- Recruitment could also be an issue if not enough schemes are willing to assist with the study or not enough carers or volunteers agree to take part. If this occurs, mentoring schemes further away from the South East of England will be contacted until the correct number of participants has been reached.

- Service providers will be asked beforehand if they have access to, or can facilitate access to counselling services. The researcher will ask participants who express high levels of depression or anxiety (based on the results of the HADS) if they would like to be referred back to the provider organisation for further emotional support. The participants will also be signposted to their General Practitioner.

Time scale and presentation of findings

The expected time scale for completion of data collection is 10 months (January to October 2013). This will allow a further 12 months for the data analysis and write up of the findings and PhD thesis. The steps to completion are: ethics approval, piloting, data collection, data analysis (data analysis will start during data collection period of the qualitative phase) and the writing up of the findings.

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Appendix 26: Consent form for carers taking part in the quantitative phase

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
Cranmer Terrace
London SW17 0RE

www.healthcare.ac.uk

Consent Form

Statement by participant

I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed of the purpose, risks, and benefits of taking part.

Project title: The impact of mentoring Schemes on Carers of People with Dementia and on Volunteer Mentors: A Mixed Methods Study

I understand what my involvement will entail and any questions have been answered to my satisfaction.

I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice.

I understand that all information obtained will be confidential, with the exception of information shared indicating a vulnerable adult is being harmed. Should this occur, I understand that this information may be shared with local authority safeguarding teams.

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.

Contact information has been provided should I (a) wish to seek further information from the investigator at any time for purposes of clarification (b) wish to make a complaint.

Participant's Signature---

Date --

Statement by investigator

I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.

Name of investigator --

-

Signature of investigator ---

-

Date ---

Appendix 27: Consent form for carers and volunteers taking part in the qualitative phase

Kingston University London
St George's University of London

Faculty of Health and Social Care Sciences
Kingston University and St George's, University of London
St George's Campus
Cranmer Terrace
London SW17 0RE

www.healthcare.ac.uk

Consent Form

Statement by participant

I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed of the purpose, risks, and benefits of taking part.

Project title: The impact of mentoring Schemes on Carers of People with Dementia and on Volunteer Mentors: A Mixed Methods Study

I understand what my involvement will entail and any questions have been answered to my satisfaction.

I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice.

I understand that all information obtained will be confidential, with the exception of information shared indicating a vulnerable adult is being harmed. Should this occur, I understand that this information may be shared with local authority safeguarding teams.

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.

Contact information has been provided should I (a) wish to seek further information from the investigator at any time for purposes of clarification (b) wish to make a complaint.

I understand that this interview will be tape recorded.

Participant's Signature--

Date ---

Statement by investigator

I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.

Name of investigator ---

Signature of investigator --

Date --