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A Contribution Towards Understanding Ways of Working With Older Adults

Diane E Greenwood

**A thesis submitted in partial fulfilment of the requirements for the
degree of Doctorate in Clinical Psychology**

**Coventry University, Faculty of Health and Life Sciences,
and University of Warwick, Department of Psychology**

August 2014

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List of Abbreviations

| | |
|-----------|---|
| CBT | Cognitive Behavioural Therapy |
| ECBT | Enhanced Cognitive Behavioural Therapy |
| DSM-IV-TR | Diagnostic and Statistical Manual of Mental Disorders, Version Four, Text Revision |
| GAD | Generalised Anxiety Disorder |
| GP | General Practice |
| NICE | National Institute for Health and Clinical Excellence |
| NHS | National Health Service |
| PCBT | Primary care Cognitive Behavioural Therapy |
| PEDro | Physiotherapy Evidence Database |
| SCID | Structured Clinical Interview for DSM Disorders |
| SIGN | Scottish Intercollegiate Guidelines Network |
| TAU | Treatment As Usual |
| UK | United Kingdom |
| USA | United States of America |

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Declaration

This thesis was carried out under supervision of Dr Jessica Bolton, Dr Carolyn Gordon and Dr Claire Pavlou. The ideas for the literature review and reflective paper were my own; the idea for the empirical paper came from a discussion with Dr James Parker, which then developed through discussions with Dr Gordon, Dr Pavlou and Dr Eve Knight. With the exception of these collaborations, the thesis is my own work. This thesis has not been submitted for a degree at any other university.

Ethical approval (Appendix A) was obtained from Coventry University Research Ethics Committee.

It is intended that Chapter 1 will be submitted for publication to Clinical Psychology Review, Chapter 2 will be submitted for publication to Dementia and Chapter 3 will be submitted for publication to Reflective Practice. Submission guidelines can be found in Appendix B.

Summary

This thesis comprises a literature review, an empirical paper and a reflective paper.

The systematic literature review involved critical assessment of eleven randomised controlled trials in which cognitive-behavioural therapy (CBT) for anxiety or depression was modified for older adults. The aim was to identify older adult-specific modifications as well as effectiveness in symptom reduction. Most commonly, modifications aimed to support understanding and homework completion, but few were age-specific. Studies comparing modified and standard CBT are lacking. Modified CBT may be more effective than wait-list, usual treatment and minimal contact. Efficacy is less clear compared with medication or an active control, and unknown compared with an alternative therapy. Future research should consider qualitative and quantitative evaluations of treatment effectiveness, and directly compare standard and modified CBT alongside an alternative therapy.

The empirical paper describes an exploration of the lived experiences of volunteer befrienders to people with dementia. Individual semi-structured interviews were conducted with nine befrienders aged between 25 and 66 years. Transcripts were analysed using Interpretative Phenomenological Analysis. The notion of the person underlies the three main themes: 'The person as the centre', 'A paradoxical relationship' and 'Core existential experiences'. Befrienders valued their befriendees' happiness and individuality, and experienced some emotional challenges. The befriending relationship was experienced as special, paradoxical and complex, and enabled befriendees to reconnect with their individuality, community and humanity. Future research should explore issues including effectiveness, attrition and support.

The reflective account summarises the helpful and challenging boundaries I experienced in conducting my doctoral research. The challenge for me was in knowing when to adapt something that was already there and when to be adaptable myself. Clinical training has developed a wide range of skills and competencies, which will be valuable in making adaptations and being adaptable as a qualified Clinical Psychologist.

Chapter 1: Literature Review

A Systematic Literature Review of Modified CBT for Older Adults with
Anxiety and Depression: What Modifications Have Been Made,
and Are They Effective?

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This chapter will be amended prior to publication in accordance with Clinical Psychology Review submission guidelines. This includes text alignment, title page information, highlights, and formatting of abbreviations and acknowledgements.

Abstract

The current paper presented a systematic literature review of studies in which cognitive-behavioural therapy (CBT) was modified for older adults with anxiety or depression. Two questions were posed: in what ways has CBT been modified for older adults, and how effective is modified CBT in reducing symptoms of anxiety and depression in older adults? Eleven randomised controlled trials comparing modified face-to-face CBT with another condition, in the treatment of older adult anxiety or depression, were critically assessed. Results indicated that CBT for older adults has been modified in numerous ways, most commonly to support understanding and homework completion, but few modifications were age-specific and studies comparing modified and standard CBT are lacking. Results also indicated efficacy of modified CBT over wait-list, usual treatment and minimal contact, but not necessarily over medication or an active control, and efficacy was unknown compared with an alternative therapy. Findings did not seem particularly reliable, however, given intervention issues and imprecise reporting. Future work should consider qualitative as well as quantitative evaluations of treatment effectiveness, and directly compare standard and modified CBT alongside an alternative therapy.

Key Words

Anxiety; Cognitive-behavioural therapy; Depression; Literature review; Modification; Older adult.

Highlights

- Systematic review of cognitive-behavioural therapy (CBT) studies with older adults.
- Examined ways to modify CBT, and effectiveness in reducing anxiety and depression.
- Common modifications supported understanding of CBT concepts and homework completion.
- Modified CBT seemed more effective than wait-list, minimal contact and usual care.
- Efficacy over active control was unclear, and over alternative therapy was unknown.

A Systematic Literature Review of Modified CBT for Older Adults with Anxiety and Depression: What Modifications Have Been Made, and Are They Effective?

Cognitive-Behavioural Therapy

Cognitive-behavioural therapy (CBT) is a structured psychotherapy that focuses on the roles of cognitions and behaviour in the onset and maintenance of mental disorders (Karlin, 2011). Such therapy “identifies habitual ways in which patients distort information”, “teaches patients to identify and respond to their dysfunctional thoughts” and “helps the patient develop new and adaptive ways of behaving” (Oude Voshaar, Hendriks, Keijers, & van Balkom, 2009, p. 2).

CBT is frequently the main psychological approach recommended in clinical guidelines for the treatment of a variety of anxiety and depressive disorders (e.g. National Institute for Health and Clinical Excellence [NICE], 2005, 2009, 2011). While these guidelines apply to adults of all ages, it has been argued that the supporting evidence is of greater quality and quantity in adult populations, and that the results may therefore not apply to older adult populations (Lindesay, Stewart, & Bisla, 2012).

CBT with Older Adults

There is currently a debate in the literature about the conclusions that can be drawn from research into CBT with older adults. Meta-analyses have reported that CBT can be efficacious in treating older people with a variety of anxiety and depressive disorders (e.g. Cuijpers, van Straten, & Smit, 2006;

Gould, Coulson & Howard, 2012a; Pincus, Duberstein, & Lyness, 2007). Similarly, literature reviews have concluded that CBT has the strongest evidence base of all therapeutic approaches (e.g. Hill & Brett, 2006; Karel & Hinrichsen, 2000) and shows clinically as well as statistically significant symptom reduction (Mohlman, 2004; Wetherell, Lenze, & Stanley, 2005).

Some authors have reported that outcomes are comparable for older and working age adults, and have therefore concluded both that older adults are as likely to benefit from therapy as working age adults (e.g. Cuijpers et al., 2006; Hill & Brett, 2005; Karel & Hinrichsen, 2000) and that very few major changes to therapy are necessary (Laidlaw, 2001; Nordhus & Pallesen, 2003). Meta-analytic research showing similar effect sizes for adults of all ages was cited in support of this argument (mean effect size $d = .72 - .78$ for older adults and $d = .73$ for working age adults). However, this research included studies in which age-related modifications were made (e.g. Gallagher & Thompson, 1982; Gallagher & Thompson, 1983; Stanley, Beck, et al., 2003; Thompson, Coon, & Gallagher-Thompson, 2001; Wetherell, Gatz, & Craske, 2003), making it difficult to draw such a conclusion. Furthermore, these findings related to psychotherapy as a whole rather than to CBT specifically.

Many authors have argued that CBT specifically appears less effective in older adults than in working age adults (e.g. Flint, 2005; Lenze & Wetherell, 2009; Mohlman, 2008). It has been reported that, for older adults compared with working age adults, studies have shown smaller effect sizes, higher attrition rates and less dramatic improvement (e.g. Covin, Ouimet, Seeds, & Dozois, 2008; Gould et al., 2012a; Shrestha, Robertson, & Stanley,

2011; Wetherell, Hopko, et al., 2005; Wetherell, Lenze, et al., 2005; Wolitzky-Taylor, Castriotta, Lenze, Stanley, & Craske, 2010). Even amongst the older adult population, it has been argued that the oldest do not benefit as much; research reports that intervention effectiveness decreased as participant age increased (e.g. Pinquart & Sörensen, 2001; Payne & Marcus, 2008). In addition, it has been reported that while CBT is more effective for older adults than wait-list or 'treatment as usual', it is not more effective than active controls or other therapeutic approaches (Cuijpers et al., 2006; Gould et al., 2012a; Wetherell, Lenze, et al., 2005).

It was therefore argued that there is a need to explore ways of improving the effectiveness of CBT for this population. Potential benefits included enhanced learning, reduced drop-out and greater symptom reduction. Indeed, clinical guidelines and many authors have recommended modifying psychotherapies in general and CBT in particular (e.g. American Psychological Association, 2004; Flint, 2005; Gould et al., 2012a; Knight & Poon, 2008; Lindesay et al., 2012; Maxfield & Segal, 2008; Pinquart & Sörensen, 2001; Shrestha et al., 2011; Wolitzky-Taylor et al., 2010).

Evidence for Modifying CBT

There are two ways in which modifying CBT for older people may increase effectiveness. Firstly, improving the acceptability of therapy may increase effectiveness via improved adherence. Missed sessions impact outcome and studies report higher attrition rates than expected in older adults (Mohlman, 2004). Also for earlier born older adults, there is a likelihood of stigma being associated with mental illness and psychotherapy

(Segal, Coolidge, Mincic, & O'Riley, 2005), or perceiving mood issues as part of normal ageing (Sarkisian, Lee-Henderson, & Mangione, 2003). These factors reduce older people's inclination to seek and accept psychological treatment, and increase the probability that they downplay their affective symptoms in therapy (Robb, Haley, Becker, Polivka, & Chwa, 2003).

Secondly, research has suggested that older adults process information differently from working age adults, which could affect CBT effectiveness. Older adults can display cognitive deficits as a result of normal aging in domains of working memory, attention, processing speed, abstract reasoning, spatial orientation and executive functioning (Mayr, Spieler, & Kliegl, 2001; Salthouse, 2004; Schaie, 2005; Zelazo, Craik, & Booth, 2003). This could limit their ability to use therapeutic techniques; for example, remember guidelines for response prevention, use hypothetical scenarios and visual imagery, and understand complex terminology (Carmin, Pollard, & Ownby, 1999; Knight & Poon, 2008). Indeed, research has reported that older people have difficulties applying cognitive techniques and strictly adhering to CBT protocols (Hendriks, Oude Voshaar, Keijsers, Hoogduin, & van Balkom, 2008; Hyer, Kramer, & Sohnle, 2004; Rainsford, 2002; Schuurmans, Emmelkamp, Weijnen, & van Dyck, 2006).

These cognitive difficulties could affect therapy effectiveness. Pilot research suggested that older adults with executive functioning impairments responded less well to CBT than those without such impairments (Mohlman & Gorman, 2005). Researchers have therefore explored ways of augmenting CBT for older people to compensate for cognitive difficulties, such as adding memory aids and techniques to facilitate homework completion. These

appeared to somewhat increase treatment efficacy compared with non-augmented versions of CBT (Gorenstein et al., 2005; Mohlman, Kleber, & Gorman, 2003). Similarly, cognitive training has successfully augmented psychotherapy in numerous other patient groups, such as those with schizophrenia, depression and stroke (e.g. Bell, Fiszdon, Bryson, & Wexler, 2004; Murray, Keeton, & Karcher, 2005; Siegle, Ghinassi, & Thase, 2007).

Modifying the Model for an Older Adult Population

The term 'modification' was used in the current paper, referring to a change "intended to enhance treatment outcome within the model of therapy", as opposed to the term 'adaptation', "intended to alert clinicians to the possibility that the treatment model they have chosen may be inadequate for the circumstances" (Laidlaw, 2001, p. 11). There have been many areas of modification suggested in the literature. These have been made to accommodate age-related changes in memory, learning and information-processing. They also consider cohort-related beliefs about mental health and psychotherapy. Four areas of modification are briefly described.

Treatment set-up. Modifications include greater structure, slower pace, shorter duration and increased number of sessions (Areán, 2004; Evans, 2007; Karlin, 2011; Myers & Harper, 2004; Payne & Marcus, 2008; Secker, Kazantzis, & Pachana, 2004). Modification of treatment duration has some empirical support; a meta-analysis by Pincus & Sörensen (2001) reported that interventions with more than nine sessions had significantly better outcome than shorter interventions, although this modification could arguably improve outcome for working age adults and older adults alike.

Ways to aid learning. In-session strategies include using age-relevant examples, eliciting participant understanding through feedback, and frequent and multi-modal summarising. Examples of memory aids include mnemonics and notebooks. Out-of-session strategies include provision of workbooks and between-session telephone calls from the therapist. Numerous authors have discussed these modifications (e.g. Hyer et al., 2004; Karel & Hinrichsen, 2000; Karlin, 2011; Knight & Poon, 2008; Payne & Marcus, 2008; Satre, Knight, & David, 2006; Wolitzky-Taylor et al., 2010).

Simplification. Examples include simplifying assignments, using lay terms instead of CBT jargon, and making use of slower, shorter and simpler phrasing when speaking (Grant & Casey, 1995; Knight & Poon, 2008; Richardson & Reid, 2006).

Reducing stigma about accessing treatment. This could include providing more psychoeducation about the nature of anxiety or depression, given possible cohort-related beliefs like depression is a sign of being “weak” or “crazy” (Karel & Hinrichsen, 2000, p. 711). It may also be less stigmatising to use the patient’s language, like talking about ‘nervousness’ instead of ‘anxiety’ (Carmin et al., 1999).

Rationale for Review

There are clearly many ways to modify CBT but the empirical basis for these is unclear, as many are recommendations based on gerontological theory. Authors have expressed that it would be useful to evaluate whether modifications increase treatment efficacy (Gould et al., 2012a; Laidlaw & McAlpine, 2008).

The current paper therefore presented a systematic and critical review of studies in which CBT has been modified for older adults with anxiety or depression.

Aim

This review aimed to answer two questions. Firstly, in what ways has CBT been modified for older adults? Secondly, how effective is modified CBT in reducing symptoms of anxiety and depression in older adults?

Method

Search Strategy

Literature searches were conducted between December 2012 and February 2013 from six sources: a) Academic Search Complete, b) PsycINFO, c) MEDLINE, d) ScienceDirect, e) Zetoc, and f) The Cochrane Library. In addition, reference lists of included papers were searched, and 'citations' and 'related records' searches were made using the PsycINFO database.

When entering search terms, an asterisk (*) was used to denote a truncation, in order to search for any words beginning with those letters. The search terms included ("CBT" OR "cognitive-behav* therapy") and ("anx*" OR "depress*"). Search terms relating to specific anxiety disorders, as defined by the DSM-IV-TR (American Psychiatric Association, 2000), were also used in order to maximise the search. Given the large number of papers generated by initial searches, additional terms were used to increase efficiency,

depending on the search mechanism in each source. All searches are detailed in Appendix C. The search strategy yielded 611 papers overall.

Selection Criteria

Papers were only included if they met all of the following criteria:

- Written in the English language.
- Published in peer-reviewed journals.
- Empirical paper.
- Randomised controlled trial.
- Only involved older adults (55+ years; lowest cut-off in literature).
- Did not involve specific population, such as medical patients.
- Research question related to anxiety and/or depression.
- Treatment was CBT (defined as such by the authors and intervention combined principles of both cognitive and behavioural therapy).
- Face-to-face therapy (not delivered by computer or telephone).
- Comparison of CBT with another condition, such as wait-list or active control.
- CBT was modified specifically for an older adult population.

These criteria were chosen in order to select high-quality studies that examined the effectiveness of modified CBT for older people with anxiety and/or depression. For the purposes of the current paper, it was decided to only review randomised controlled studies, as case studies and formulation-based interventions often tailor intervention for individual needs. Papers were limited to studies involving face-to-face therapy, rather than bibliotherapy or computerised therapy, because method of delivery may affect treatment

engagement and outcome. Similarly, studies involving specific populations were excluded because these populations may present specific issues that could affect treatment engagement and outcome. Therapy format was not an exclusion criterion, as research suggests that both individual and group therapy can be beneficial with older people (e.g. Areán & Miranda, 1996, as cited in Areán et al., 2005).

Article abstracts and methodologies were read in order to check suitability. The exclusion process is illustrated in Figure 1.

Eleven papers met the criteria and were included in the current review. The main aspects and findings of these papers are summarised in Appendix C.

In the current review, the term 'study' referred to the trial that was conducted, whereas the term 'paper' referred to the report written about that study. This was an important distinction in this review, as one paper related to two studies (Mohlman et al., 2003), and two papers reported post-treatment and follow-up data respectively from the same study (Schuurmans et al., 2006; Schuurmans et al., 2009).

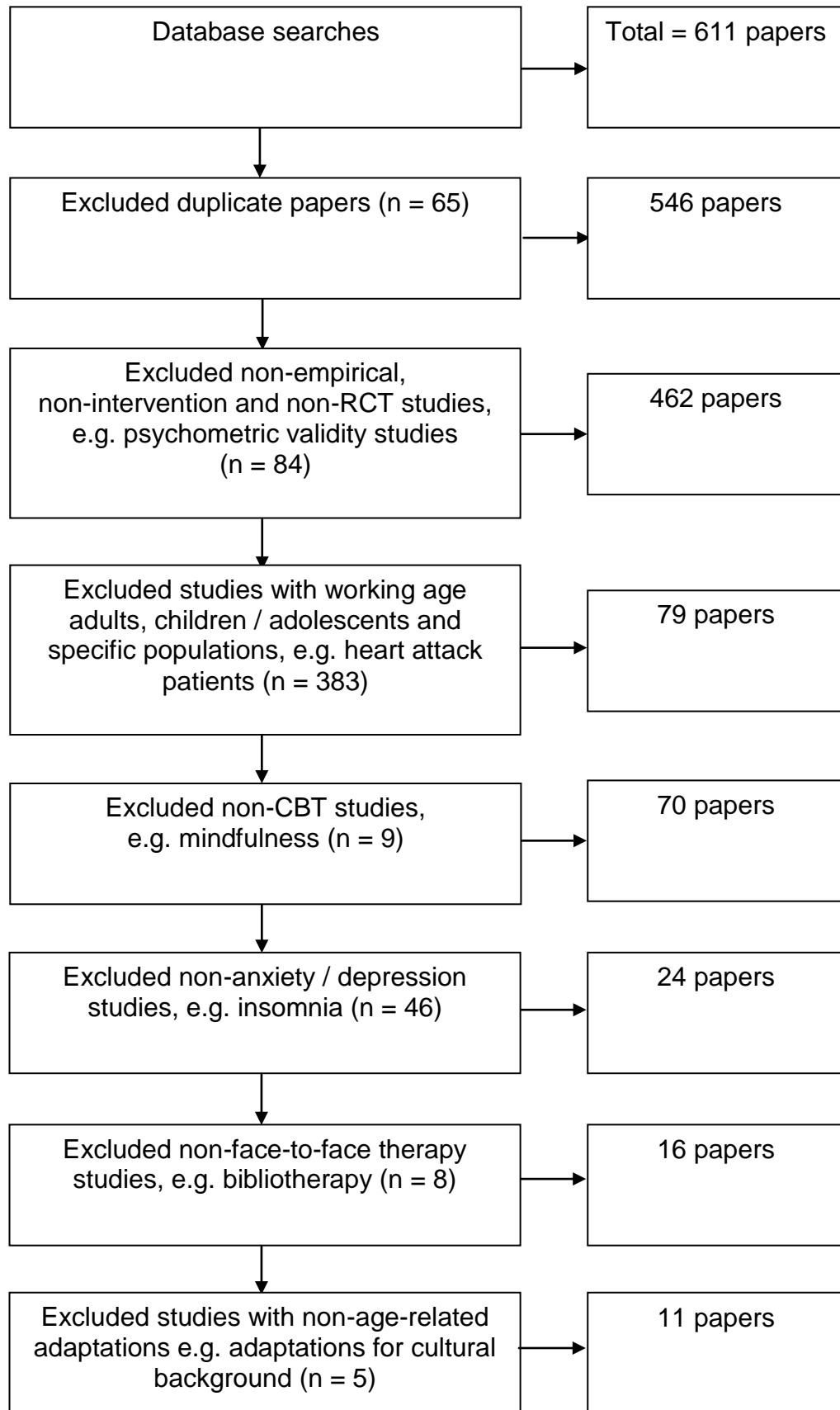


Figure 1. Exclusion process during literature search.

Quality Assessment

Methodological quality of the studies was assessed using the PEDro Scale (Maher, Sherrington, Herbert, Moseley, & Elkins, 2003). This was developed specifically to assess the quality of randomised controlled trials and has been deemed to have acceptable reliability (Maher et al., 2003). Two items were removed, however: Item 8, as this does not relate to methodological quality, and Item 1, as it is not scored (Maher et al., 2003). Papers could therefore score a maximum of 9 points. A 'high quality' paper scored 5 points or more; the original cut-off score was 6 (Maher et al., 2003) but this was adjusted by 1 point here to take account of removing Item 8.

In order to assess the reliability of this quality rating, a supervisor of the author acted as second reviewer and rated three papers. Inter-rater reliability was high ($\alpha = .86$). Discrepancies were discussed and resolved.

The final quality ratings according to the PEDro Scale are summarised in Figure 2. Scores indicated that all papers were of high quality. All study designs involved random and concealed allocation, and all papers presented between-group statistical comparisons, point measures and variability data. Six to eight of the 11 studies matched groups at baseline, had blinded assessors and conducted intention-to-treat analysis. None had blinded subjects and only one had therapists that were blind to treatment condition.

| | Random allocation | Concealed allocation | Groups similar at baseline | Subject blinding | Therapist blinding | Assessor blinding | Intention-to-treat analysis | Between-groups statistical comparisons | Point measures and variability data | Total points (max. 9) |
|--------------------------|-------------------|----------------------|----------------------------|------------------|--------------------|-------------------|-----------------------------|--|-------------------------------------|-----------------------|
| Areán et al. (2005) | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 1 | 1 | 6 |
| Laidlaw et al. (2008) | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 1 | 6 |
| Mohlman (2008) | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 1 | 1 | 6 |
| Mohlman et al. (2003) | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 1 | 1 | 6 |
| Schuermans et al. (2006) | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 6 |
| Schuermans et al. (2009) | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 6 |
| Serfaty et al. (2009) | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 6 |
| Stanley et al. (2003a) | 1 | 1 | 1 | 0 | 0 | 1 | 1 | 1 | 1 | 7 |
| Stanley et al. (2003b) | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 5 |
| Thompson et al. (2001) | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 6 |
| Wetherell et al. (2003) | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 6 |

Figure 2. Summary of quality ratings of included papers.

Critique of Papers

Critique of the papers was provided in the current report, in order to complement the quality assessment and offer a more comprehensive review. This critique considered criteria used by numerous organisations and authors, to provide consistent and clinically appropriate evaluation (e.g. Cartwright-Hatton, Roberts, Chitsabesan, Fothergill, & Harrington, 2004; Critical Appraisal Skills Programme, 2010; Effective Public Health Practice Project, 2009; Scottish Intercollegiate Guidelines Network [SIGN], 2012; Waxman, 2009).

Results

Question 1: In What Ways Has CBT Been Modified for Older Adults?

The modifications made in each study are detailed in Appendix C. The most commonly-used modifications came under the themes of ‘facilitation of learning and recall’ (theme 1) and ‘emphasis on and support with homework’ (theme 2). Modifications were least common in relation to ‘age-relevant content’ (theme 3). The identified modifications generally seem in line with existing literature.

Considerable subjectivity was noted in some papers. Areán et al. (2005) simply reported that modifications were made under author guidance, meaning there was no apparent empirical basis or rationale for these. Furthermore, Laidlaw et al. (2008) used a treatment manual developed specifically for the study, yet the empirical basis for this is unclear.

In addition, it was observed that some of the modifications may not necessarily be age-specific. It is possible that there are age-related information-processing difficulties, so modifications such as using less CBT jargon, providing homework support and presenting material using different modalities may indeed be more relevant for older people. Such modifications could, however, be helpful with any population. Arguably there were few age-specific modifications; for example, addressing specific age-related issues in sessions, offering home visits for those unable to travel, and making examples more relevant to older people.

Similarly, age-specific modification to CBT termination was noticeably lacking amongst the studies reviewed. Given that loss often plays a large role in late life, older clients may find CBT termination more emotionally acceptable when sessions are gradually tapered-off (Karlin, 2011; Secker et al., 2004); however only one intervention reduced the frequency of the final two CBT sessions (Areán et al., 2005).

These points indicated that there appeared to be few age-specific modifications made to CBT with older people, and that the empirical basis for some modifications is lacking.

Question 2: How Effective is Modified CBT in Reducing Symptoms of Anxiety and Depression in Older Adults?

Papers were reviewed according to diagnostic group: a) anxiety disorders, and b) depression. Where applicable, they were then reviewed according to therapy format (individual vs. group).

Anxiety disorders.

Individual interventions. Four papers were discussed here. Two related to anxiety disorders (Generalised Anxiety Disorder [GAD], panic disorder, agoraphobia or social phobia). These were discussed first.

Schuurmans et al. (2006, 2009) reported post-treatment and one year follow-up data respectively on CBT, medication (sertraline) and wait-list. Outcomes were reportedly similar at post-treatment and follow-up. Intention-To-Treat analyses showed no significant differences between treatment groups. In completer analyses, the sertraline group showed more improvement on worry and anxiety symptoms than CBT or wait-list groups, and effect sizes remained small to moderate for CBT ($d = 0.22-0.70$) but moderate to large for sertraline ($d = 0.60-1.62$). It was concluded that long-term use of sertraline may be more beneficial for late-life anxiety than a 15-session CBT programme.

It was noted, however, that sertraline was maintained during follow-up in at least 50% of sertraline participants, which biased results. Furthermore, the conclusion about the benefit of long-term sertraline use may not be reliable for three reasons: a) worry symptoms were a secondary outcome measure, b) benefit of sertraline over CBT on worry symptoms was not reported in the Results section of the paper, and c) Intention-To-Treat analyses showed no significant differences between treatment groups. In addition, readers should be mindful that the study is not sufficiently powered, and that results cannot be generalised to other anxiety disorders such as specific phobia, obsessive-compulsive disorder or post-traumatic stress disorder as these were excluded from the study.

According to SIGN (2012), if groups were not treated equally or if main conclusions were based on secondary outcomes, the study should be rejected unless no other evidence is available. As Schuurmans et al. (2006, 2009) was the only study in the current review relating to multiple anxiety disorders it was used as evidence, but results should be treated with caution.

There were two further papers relating to anxiety disorders, specifically to GAD. The first, by Mohlman et al. (2003), reported two studies in which wait-list was compared with a) standard CBT, and b) CBT enhanced with learning and memory aids (Enhanced CBT; ECBT).

GAD severity significantly reduced for CBT ($\eta^2 = 0.27$) and ECBT ($\eta^2 = 0.49$) participants, compared with wait-list participants. Also, at post-treatment, significantly fewer ECBT participants met response criteria, compared with wait-list (data insufficient to calculate effect sizes). Furthermore, ECBT resulted in significant improvements on a) an anxiety and worry composite variable ($\eta^2 = 0.49$), b) a psychological distress subscale ($\eta^2 = 0.40$), and c) GAD rates ($\eta^2 = 0.61$), whereas wait-list did not.

Some variables in this study, such as 'homework quality', were not defined. This made it more difficult to associate these variables with treatment outcome, as proposed by the authors, and was considered a limitation of the study.

The second paper relating to GAD was by Stanley, Hopko, et al. (2003), who compared usual care with a version of CBT that is older adult-, GAD- and primary care-specific (Primary care CBT; PCBT).

For PCBT compared with usual care participants, GAD severity significantly reduced ($\eta^2 = 0.69$) and significantly fewer participants met

response criteria at post-treatment ($\eta^2 = 0.67$). Also, PCBT resulted in significant reductions in worry ($\eta^2 = 0.38$) and depression ($\eta^2 = 0.60$), whereas wait-list did not.

It was unclear from the paper what intervention was actually provided to participants, as it was stated in the Discussion but not the Method section that participants in the CBT group also received usual care. This lack of clarity made it more difficult to draw clinically meaningful conclusions. Also, statistical reporting was poor in this paper; for example the p-values were not always reported, which limits data utility.

In both the Mohlman et al. (2003) and the Stanley, Hopko, et al. (2003) studies, the same measures were used to assess anxiety, worry and depression, and response criteria were similarly defined as 20% reduction on a) two out of three measures of worry and anxiety (Stanley, Hopko, et al., 2003), or b) 75% of outcome measures (Mohlman et al., 2003). GAD severity, however, was assessed slightly differently. Mohlman et al. (2003) used the SCID whereas Stanley, Hopko, et al. (2003) used clinician ratings; while these were based on the GAD section of the SCID, there is potentially more subjectivity than in the Mohlman et al. (2003) study. In addition, neither of the studies reported GAD severity of the sample at baseline.

Results of the two GAD studies indicated that individual modified CBT may have significantly reduced both GAD symptomatology and GAD severity, though the latter claim appeared less reliable.

Group interventions. Three papers were discussed. Modified CBT, based on similar published procedures, was compared with minimal contact

(Stanley, Beck, et al., 2003) and both a discussion group and wait-list (Wetherell et al., 2003). These two papers were discussed first.

At post-treatment in Stanley, Beck et al.'s study (2003), modified CBT showed significant benefits on anxiety ($\eta^2 = 0.47$), worry ($\eta^2 = 0.25$), depression ($\eta^2 = 0.33$) and quality of life ($\eta^2 = 0.26$), compared to minimal contact. At post-treatment in Wetherell et al.'s study (2003), modified CBT showed significant benefits compared with wait-list on GAD severity ($\eta^2 = 0.60$), worry ($\eta^2 = 0.31$), depression ($\eta^2 = 0.39$) and two quality of life measures: "role functioning" ($\eta^2 = 0.41$) and "energy/vitality" ($\eta^2 = 0.41$). Modified CBT also showed significant benefits compared with the discussion group on the measure "percentage of day worried" ($\eta^2 = 0.38$). Stanley, Beck et al. (2003) found benefits were maintained at 1-year follow-up; however Wetherell et al. (2003) found no differential treatment effects between CBT and the discussion group at 6-month follow-up.

Stanley, Beck, et al. (2003) implemented thorough procedures to assess the reliability of a GAD diagnosis, but agreement over time was only "fair"; this should be considered a limitation of the study. Other limitations include inadequate test-retest reliability in two key outcome measures and additional treatment for six minimal contact participants, both of which could affect the reliability of the data.

The Wetherell et al. (2003) study was the only one in the current review to include two control groups (a discussion group and wait-list) and to include homework in the discussion group condition. This provided some control for non-specific therapy factors. Unfortunately, therapist bias was highlighted, as most therapists reported stronger allegiance to CBT than to

the discussion group. Furthermore, there was variability associated with different therapists: participants in the principal investigator's CBT groups had lower attrition rates, higher attendance, better homework compliance and better outcomes than participants in groups led by other therapists. As acknowledged by the authors, these factors make it difficult to attribute the study findings to treatment as opposed to therapist factors. Results may be different if replicated with a more uniform group of therapists.

The third paper relating to group GAD interventions (Mohlman, 2008) compared two versions of modified CBT, one of which included executive skills training. At 6-month follow-up, CBT plus executive skills training yielded more participants who met criteria for response ($\eta^2 = 0.56$) and high end-state functioning ($\eta^2 = 0.56-0.67$) than CBT alone. Limitations, as acknowledged by the author, include a small sample (eight), lack of a no-treatment control group, lack of neuropsychological follow-up and the possibility of progressive cognitive impairment within the sample.

Results of these studies indicated that group CBT may have a significant and long-term effect on a) GAD rates; b) end-state functioning; c) symptoms of anxiety, worry and depression; and d) quality of life. There was, however, little evidence to support the efficacy of CBT over an active control.

Depression.

Individual interventions. Three papers were discussed here. Laidlaw et al. (2008) compared CBT with treatment as usual (TAU). Serfaty, Haworth, & Buszewicz (2009) compared TAU, TAU plus a talking control, and TAU plus CBT. Thompson et al. (2001) compared CBT, medication (desipramine) and both combined.

Compared with controls, CBT participants showed greater reductions in depression ($\eta^2 = 0.14$) and hopelessness ($\eta^2 = 0.16$) scores at 6-month follow-up (Laidlaw et al., 2008) and at 10-month follow-up (data insufficient to calculate effect sizes, Serfaty et al., 2009). Fewer CBT than control participants met DSM-IV criteria for a depression diagnosis at 3-month follow-up ($\phi = .53$, Laidlaw et al., 2008). At 3-4 month follow-up, a combination of CBT and medication resulted in greater improvement in depression symptoms than medication alone ($\eta^2 = 0.47$), and there was no significant difference in improvement between the CBT and CBT-medication combination conditions (statistics not cited, Thompson et al., 2001).

Sample sizes in the Serfaty et al. (2009) study (204 participants) and Thompson et al. (2001) study (102 participants) were some of the largest in this review. Also, randomisation procedures in these two studies were some of the most rigorous in comparison with other studies in the current review, using computer-generated random numbers and independent staff. In addition, Laidlaw et al. (2008) reported that “therapists were blind to treatment condition” (p. 844), which potentially minimised the effect of therapist factors on results. Furthermore, use of an active control by Serfaty et al. (2009) enabled more meaningful conclusions about CBT efficacy.

There were, however, intervention issues in the three studies that may limit their reliability. Prescriptions indicated that medication was not at a therapeutic dose, or was commenced or discontinued, during the study period (Serfaty et al., 2009; Thompson et al., 2001). Participants received additional treatment (Laidlaw et al., 2008; Serfaty et al., 2009), and there was large variability in the number of CBT sessions received (range 2-17; Laidlaw

et al., 2008). Therapists also reported greater allegiance to CBT than the talking control (Serfaty et al., 2009).

In addition, depression severity in two of the samples was unclear (Laidlaw et al., 2008; Thompson et al., 2001). Study titles referred to mild-to-moderate depression; however the studies may have excluded people with mild depression by setting the cut-off threshold for exclusion too high on the Beck Depression Inventory (scores of over 13 and 18 respectively; see Beck, Steer, & Garbin, 1988, for discussion of various cut-off score ranges).

Finally, the reporting of some results could bias the conclusions. In Laidlaw et al.'s (2008) study, not all outcome measures were discussed, and some results were reported for 3- but not 6-month follow-up. Also, reduction in scores was discussed in terms of which treatment condition had a better reduction than the other, as opposed to whether score reductions themselves were significant. It is important to be able to draw clinically meaningful conclusions from these studies, not just comparative effects. Finally, in Thompson et al.'s (2001) study, the only instance where combined treatment was more effective than CBT alone appeared to occur in the more severely depressed group, who were receiving higher levels of medication than less severely depressed participants. Thus, caution is urged about drawing conclusions about benefits of medication for depression in general.

Results of these studies indicated that individual CBT may have significant and sustained effects on symptoms and rates of depression; however results did not seem particularly reliable given the intervention issues and imprecise reporting.

Group interventions. Areán et al. (2005) compared the efficacy of clinical case management, group CBT and a combination of the two in the treatment of depressed, low-income older adults. Results indicated that the CBT group showed a more significant improvement in functioning than the case management ($d = 0.52$) or combination ($d = 0.36$) treatment groups. In contrast, the CBT group showed less significant improvement in depressive symptoms than the case management ($d = 0.44$) or combined treatment groups ($d = 0.56$).

Some intervention issues were noted in this study. For example, it was unclear why “each group member repeated one of the modules depending on when he or she entered treatment” (Areán et al., 2005, p. 603). This raised a question about the standardisation of the therapeutic treatment across participants. It was also noted that participants in the combined treatment group typically had more visits to the clinic than participants in the other two groups, as case management and CBT were separate interventions. Finally, numerous participants sought additional post-treatment support, such as medication or seeing a therapist for individual therapy. This could have affected the results, as the main differences in depression scores between groups only became apparent at follow-up.

The study findings did not clearly indicate CBT efficacy in reducing depressive symptoms in this population.

Summary of findings.

Anxiety disorders. Results suggested that individual CBT may be more effective than wait-list or usual care in reducing anxiety, worry, GAD symptoms and GAD severity, but less effective than medication; however

significant study concerns mean results in relation to anxiety and worry should be treated with caution. Findings also indicated that group CBT may be more effective than minimal contact or wait-list on a) GAD rates; b) end-state functioning; c) symptoms of anxiety, worry and depression; and d) quality of life. There was little support for CBT efficacy over an active control.

Depression. Results indicated that individual CBT may be more effective in reducing symptoms and rates of depression, compared with an active control, treatment as usual, medication and wait-list. However, findings did not clearly indicate efficacy of group CBT in reducing depressive symptoms in low-income older adults.

Discussion

Question 1: In What Ways Has CBT Been Modified for Older Adults?

There were four themes of modification. Most commonly, CBT was modified to support homework completion and to facilitate learning and recall. This is consistent with research suggesting homework adherence may significantly predict CBT outcome for older adults (e.g. Wetherell, Lenze, et al., 2005).

The existence of common modifications across studies might indicate that homework completion and client understanding of CBT concepts may be considered to influence treatment outcome in older adults. To the author's knowledge, there is no evidence of clinicians' views of the active components of CBT in the literature, but further research could investigate this, for example using a Delphi study.

Most modifications in this review showed consistency with those highlighted in the existing literature, which were discussed earlier in relation to a) treatment set-up (e.g. Evans, 2007; Payne & Marcus, 2008; Secker et al., 2004); b) ways to aid learning (e.g. Hyer et al., 2004; Payne & Marcus, 2008; Satre et al., 2006); and c) simplification (e.g. Grant & Casey, 1995).

There were three exceptions. The first was renaming interventions to reduce stigma about accessing treatment, as done in the current review by Wetherell et al. (2003). This concept is not expressed directly in the literature, but is consistent with previously discussed research about considering language use and impact of cohort-related beliefs (Carmin et al., 1999; Karel & Hinrichsen, 2000). Furthermore, other mental health studies with older adults have modified language to increase recruitment (e.g. Csipke, Serfaty, & Buszewicz, 2006).

The second exception was making some of the intervention content age-relevant, as done by Mohlman et al. (2003), Serfaty et al. (2009) and Wetherell et al. (2003). It has been recommended that clinicians consider the impact of cohort-related perspectives on content (e.g. American Psychological Association, 2004), but there is little literature on modifying content to make it more relevant for older adults.

Finally, Mohlman et al. (2003) added an executive skills rehabilitation programme to CBT, in an attempt to improve the skills needed for successful control of negative affect (e.g. Derryberry & Reed, 2002). While similar studies are lacking, this concept is consistent with research indicating the role of reduced executive functioning in late-life anxiety (Price, Eldreth, & Mohlman, 2011).

Question 2: How Effective is Modified CBT in Reducing Symptoms of Anxiety and Depression in Older Adults?

Anxiety disorders. Consistent with Schuurmans et al.'s (2006, 2009) findings, meta-analyses and literature reviews regarding anxiety disorders indicate CBT efficacy compared with wait-list (Gould et al., 2012a; Hendriks et al., 2008). Aside from Schuurmans et al. (2006, 2009), only one other study has compared CBT with pharmacotherapy for late-life anxiety, specifically in panic disordered patients (Hendriks et al., 2010). Findings indicated efficacy of both CBT and medication compared with wait-list. Medication appeared slightly more effective than CBT regarding a) panic-free status, which is consistent with Schuurmans et al.'s (2006, 2009) findings; and b) general psychological symptom reduction, inconsistent with Schuurmans et al. (2006, 2009).

In terms of GAD, current findings were similar to those in existing analyses and literature reviews. These indicated that a) the largest gains tend to be for individual rather than group CBT (e.g. effect sizes for individual versus group CBT were -1.72 and -.91 respectively, Covin et al., 2008); b) some CBT outcomes may be comparable to other therapies, including applied relaxation therapy, non-directive therapy and supportive therapy (Fisher & Durham, 1999; Mohlman, 2004).

Depression. Current findings indicated some efficacy of individual but not group CBT; however existing meta-analyses reported no difference between individual and group format in CBT efficacy (e.g. Cuijpers et al., 2006). The characteristics of Areán et al.'s (2005) sample may therefore have influenced findings relating to group CBT. Indeed, comparable results

were reported in samples of younger adults with similar characteristics (e.g. Miranda, Azocar, Organista, Dwyer, & Areán, 2003).

Current results were consistent with existing literature reporting efficacy of individual CBT over wait-list and usual care, but were inconsistent with existing literature where efficacy over other psychotherapies or medication is unclear (Areán, 2004; Cuijpers et al., 2006; Frazer, Christensen, & Griffiths, 2005; Gould et al., 2012b; Pinquart et al., 2007). This may be explained by previously mentioned intervention issues and imprecise reporting in current studies.

Clinical Implications

Overall, findings indicated efficacy of modified CBT in reducing depression and anxiety symptoms compared with wait-list, minimal contact and usual treatment, though not compared with an active control. Findings did not seem particularly reliable, however, given the issues raised in the current review. There was a larger effect size for modified CBT than standard CBT in GAD patients (Mohlman et al., 2003); however there was no direct comparison between the interventions, or comparison with another therapy in any of the studies, thus evidence is lacking for differential therapy efficacy.

Given the variety of modifications used and the lack of direct comparison between modified and standard CBT, the effect of particular modifications on CBT outcome was unclear. Specific modifications therefore cannot be recommended.

Some interventions in the current review were lengthened (e.g. Serfaty et al., 2009). This is recommended in the literature (e.g. Payne & Marcus, 2008), but implications of longer treatment have raised concern. For example, Schuurmans et al. (2009) highlighted logistical problems for older adults such as transportation, as well as the psychological strain involved in psychotherapy; therefore development of shorter-term psychotherapies that can be delivered at home or in a primary care setting was recommended, in order to make psychological intervention more accessible to this client group.

Research Implications

There is much debate in the literature about treatment efficacy for older adults, and research currently indicates that CBT outcomes could be enhanced. It may therefore be appropriate to investigate the mechanisms of CBT further with this population. The Medical Research Council (2008) has recommended a phased approach to the development and evaluation of complex interventions. According to their published guidelines, this involves a) systematic intervention development, based on appropriate theory and best available evidence; b) testing of interventions through a series of pilot studies targeted at each of the key design uncertainties; c) exploratory and then definitive evaluation (Medical Research Council, 2008, p. 8).

While some theoretical basis for modifying CBT can be found in the literature, the current review noted a lack of evidence for the modifications made to CBT in the studies reviewed. There was also a lack of feasibility or pilot work exploring the mechanisms of standard and modified therapeutic approaches with older adults. In line with the above guidelines, it is

recommended that such work is conducted prior to further evaluation. This is in order to a) build good theoretical understanding of change mechanisms, so that weak links in the causal chain can be identified and strengthened; b) enable distinction between intervention ineffectiveness and implementation failure.

Recommendations for future research also include a) recruiting larger and more representative samples of older adults; b) reporting outcomes in terms of effect sizes; c) exploring treatment effects with other clinical presentations, such as specific phobia; d) using a range of outcome measures.

A different research question may complement this process. Research has commonly investigated therapy-specific factors that could influence the change process, but this approach neglects a host of individual factors. For example, studies suggest that attitudes towards and preference for treatment may significantly contribute to outcome (Lin et al., 2005; Sirey, Bruce, & Alexopoulos, 2005). Given that research does not consistently support efficacy of CBT over other therapies, it could be helpful to explore non-specific treatment factors that might enhance outcome. Qualitative research into patient experiences of treatment may further our understanding of treatment mechanisms, which could then be investigated more rigorously with a controlled design. Clinically, the value of challenging assumptions about ageing, and of working with the individual rather than the age, may have been underestimated.

Review Limitations

The quality framework selected was developed for use with physiotherapy trials and has not been validated with a clinical population, although it has been used in other systematic reviews of psychological interventions (e.g. Soo & Tate, 2007). Also, it is highlighted that the scoring of quality scales relies on report detail rather than study conduct. Readers are cautioned against relying on this as a sole indicator of study validity.

The narrow inclusion criteria meant that a) there were few studies in the current review that related to each clinical presentation, which limited the available evidence base; b) conclusions of the review only related to a specific area of modified CBT for older adults. Papers were excluded that could have contributed to the wider evidence base on modified CBT with older adults, including a) non-randomised studies (e.g. Turner, Steketee, & Nauth, 2010); b) other older adult populations, such as those in long-term care (e.g. Konnert, Dobson, & Stelmach, 2009); c) other therapeutic modifications, such as incorporating religion and spirituality into psychotherapy (e.g. Paukert et al., 2009); d) other mediums of treatment delivery, such as the Internet (e.g. Zou et al., 2012); e) qualitative research providing patient and carer perspectives on treatment efficacy (e.g. Ayers, Bratitotis, Saxena, & Wetherell, 2012). Papers relating to other mental health disorders such as specific phobia (e.g. Pachana, Woodward, & Byrne, 2007) and to studies conducted outside the USA or Europe (e.g. Nance, 2012) were also excluded; however this was inadvertent as they were excluded on the basis of criteria relating to methodology or client group.

In addition, the methodology of the current review was relatively subjective, and the author's own biases may have influenced the critique of treatment effectiveness. Meta-analysis may provide a more objective review of the evidence and allow clearer comparison between studies.

Finally, the current review did not consider the variability in expertise of staff who delivered the interventions. This could have important cost and training implications.

Conclusions

Firstly, CBT for older adults has been modified in numerous ways, most commonly to support understanding and homework completion, but few modifications were age-specific and studies comparing modified and standard CBT are lacking. Secondly, while evidence in the current review generally appeared to indicate efficacy of modified CBT compared with wait-list, usual treatment and minimal contact, efficacy was less clear compared with medication and an active control, and efficacy compared with an alternative therapy was unknown. Finally, although older adults appeared to benefit from CBT, results indicated that there is still room for considerable improvement in our understanding and treatment of anxiety and depressive disorders in older adults. It is recommended that future work considers qualitative as well as quantitative evaluations of treatment effectiveness, and directly compares standard and modified CBT alongside an alternative therapy.

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Chapter 2: Empirical Paper

The Person as Paramount:

A Qualitative Exploration of the Experiences of Volunteer Befrienders
to People With Dementia

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Abstract

This qualitative study explored the lived experiences of volunteer befrienders to people with dementia. Individual semi-structured interviews were conducted with nine befrienders aged between 25 and 66 years. Transcripts were analysed using Interpretative Phenomenological Analysis. The notion of the person underlies the three main themes encompassing befrienders' experiences: 'The person as the centre', 'A paradoxical relationship' and 'Core existential experiences'. Befrienders saw beyond the dementia stereotype and valued their befriender's individuality and happiness. They also valued their relationship with their befriender, despite its paradoxical complexities and emotional challenges. For befrienders, this relationship characterised befriending as a personal, emotional and experiential phenomenon, enabling befrienderes to reconnect with their individuality, community and humanity. Publicising these findings could help to challenge the stigma around dementia and to enhance recruitment and support of dementia befrienders. Future research should explore issues including effectiveness, attrition and support.

Key Words

Befriender; Community; Dementia; Qualitative; Volunteer.

The Person as Paramount: A Qualitative Exploration of the Experiences of Volunteer Befrienders to People With Dementia

Introduction

Dementia: Definition and Prevalence

According to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), dementia involves substantial decline in one or more cognitive domains (e.g. memory, attention, language and perception); this decline a) interferes with independence, b) occurs outside a delirium context, and c) is not primarily attributable to another mental disorder. In the United Kingdom (UK), it is estimated that dementia currently costs more than stroke, heart disease and cancer combined and will affect one million people by 2025 (Alzheimer's Society, 2007). Furthermore, it is the leading cause of disability in later life and people with dementia have reported loss of independence, self-esteem, control and close relationships (Alzheimer's Society, 2007; de Boer et al., 2007).

Voluntary Sector Involvement in Dementia Care

Current dementia services include hospital, residential and community-based care (Alzheimer's Society, 2013a; Audit Commission, 2002). Increasingly, there has been a focus on community-based care, in order to support the wishes of people with dementia and their families and to reduce the cost of care (Audit Commission, 2000).

It is recommended that models of dementia care integrate the public, private and voluntary sectors (e.g. Health Foundation, 2011). Governmental policies and clinical guidelines repeatedly highlight the key role of the voluntary sector in integrated dementia service provision (Audit Commission, 2002; Care Service Improvement Partnership, 2005; Health Foundation, 2011; Department of Health, 2001; National Institute for Health and Clinical Excellence (NICE), 2006). Voluntary organisations have been described as providing essential community-based services to enable people to continue living in their own homes (Audit Commission, 2000; Health Foundation, 2011). Voluntary organisations have grown considerably in the UK and will have an increasingly important role as dementia services are localised more in the community (Health Foundation, 2011; Knapp, Comas-Herrera, Somani, & Banerjee, 2007).

Volunteers and Volunteer Befrienders in Dementia Care

Volunteer involvement has been described as an important component to the provision of community-based dementia services (Alzheimer's Society, 2013b; Audit Commission, 2002; NICE, 2006). Volunteers include unpaid campaigners, advisors and facilitators of social and leisure activities, as well as befrienders (Alzheimer's Society, 2013c).

Befrienders offer a relationship that 'is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit [...] [it] is non-judgemental, mutual, purposeful, and there is a commitment over time' (Dean & Goodlad, 1998, p. 2). This is different from friendship, defined in the literature as a voluntary affective tie between two

individuals (de Medeiros, Saunders, Doyle, Mosby, & Van Haitsma, 2011). Befriending services function as a route to 'normalisation', in keeping with the underlying philosophy of community care whereby people fit into typical societal patterns of everyday life (Heslop & Robinson, 2004). Befriending has also been considered one way to address issues of social isolation, loneliness and depression, through promoting choice, inclusion and independence (Heslop & Robinson, 2004). These are issues affecting diverse groups, including people with disabilities and mental health needs, but have been highlighted specifically by people with dementia (Alzheimer's Society, 2007; de Boer et al., 2007; Heslop & Robinson, 2004). In the UK, over 500 voluntary organisations offer befriending services, virtually all of which are delivered by volunteers (Dean & Goodlad, 1998). Outcomes include reduced loneliness and worry, and increased social interaction, peer support and self-esteem (Windle, Francis, & Coomber, 2011).

The clinical efficacy of befriending people with dementia has not been rigorously studied, but has been discussed in terms of value. People with dementia have reported that befrienders meet an emotional need for companionship, provide social and intellectual stimulation, help them to cope with dementia and enhance their quality of life (Alzheimer's Society, 2013a; Moyle et al., 2011; Preston, Marshall, & Bucks, 2007). Befrienders have also been praised by GPs and carers and are recognised in clinical guidelines as valuable in dementia care (Audit Commission, 2002; NICE, 2006).

It has been recommended that befriending services for people with dementia are to be increased and both service evaluations and funding for randomised controlled trials have been set up (Audit Commission, 2002;

National Audit Office, 2007). However, there are reportedly befriender shortages and befriender waiting lists (Dean & Goodlad, 1998; N. Lavin, personal communication, October 25, 2013; T. McDermott, personal communication, December 9, 2013). A survey of other sector befriending services, such as for older people and people with disabilities, reported that two-thirds of services have problems attracting befrienders and one third have high befriender turnover (Dean & Goodlad, 1998).

There has been little research exploring the experiences of befrienders or other volunteers in dementia care, despite this being highlighted as an important area for research (Smith & Greenwood, 2013). In Dean and Goodlad's (1998) survey of other sector befriending services, befrienders highlighted the importance of talking and taking a personal interest in the client. In questionnaires and interviews, befrienders to people with learning disabilities reported mixed emotional experiences and a sense of helping others (Heslop & Robinson, 2004). In a quantitative study, Chung (2008) found that volunteers who delivered a reminiscence programme to people with dementia a) showed positive appreciation of older people, and b) identified a heavy workload. Guerra, Demain, Figueiredo and De Sousa (2012) conducted 15-minute interviews with volunteers who provided meaningful occupation to people with dementia while carers attended a support group. It was reported that volunteers felt more empathy towards people with dementia and experienced personal and professional growth.

Themes in existing research therefore relate to volunteers' perceptions of people with dementia, professional development and personal involvement. This evidence base does not include the area of dementia

befriending, however. Literature with paid dementia workers and volunteers in other sectors will therefore be considered to help understand the possible issues for dementia befrienders.

Research With Paid Dementia Workers and Other Sector Volunteers

Workers and other sector volunteers included a) paid dementia workers, such as nurses, care workers and physicians; b) palliative volunteers, who support people who are nearing the end of life or have a chronic disease, which is relevant as dementia is a progressive and terminal condition (Lloyd-Williams & Payne, 2002); c) volunteers who support people without a clinical diagnosis, such as older people.

Role definition. A key theme in the literature relates to workers' and volunteers' perception of their role and its boundaries. For example, Stockwell-Smith, Jones and Moyle (2011) found that one group of paid dementia workers perceived their role as a series of tasks. However, other studies found that workers and volunteers regarded their role as helping and making a difference to clients' quality of life (Cook, Fay, & Rockwood, 2012; Pennington & Knight, 2008).

Research has suggested that maintaining the boundaries of their role can be a challenge for both workers and volunteers (e.g. Ryan, Nolan, Enderby, & Reid, 2004; van Dijk, Cramm, & Nieboer, 2013). Role clarity has been found to be particularly important for volunteers in terms of their role expectations, personal development and emotional coping (e.g. Akintola, 2008; Fitzpatrick, Edgar, Remmer, & Leimanis, 2013).

Emotional experiences. Another salient theme in the literature relates to how workers and volunteers felt in their role. Workers and volunteers reported pleasure and fulfilment from their work and valued their relationships with clients (e.g. Pennington & Knight, 2008; Ryan et al., 2004; Sung, Chang, & Tsai, 2005). However, workers and volunteers have also reported various difficult emotions, including anxiety, frustration and guilt (e.g. Akintola, 2008; Cook et al., 2012; Guerra et al., 2012). Studies involving volunteers have found they felt demotivated and discouraged, particularly when they felt ineffective (e.g. King, Lloyd, Clune, & Allan, 2009; Kristiansen, Hellzén, & Asplund, 2006; Rath, 2008). Ongoing professional support was cited as important for workers and volunteers, and was linked with wellbeing, work-life balance, and job satisfaction (e.g. Brown, 2011; Chenoweth, Jeon, Merlyn, & Brodaty, 2010; van Dijk et al., 2013). It has been highlighted that understanding workers' experiences can help to identify appropriate support and training, which in turn can positively influence satisfaction and wellbeing (e.g. Kristiansen et al., 2006; Stockwell-Smith et al., 2011).

Rationale for the Current Study

Befriending is valued in dementia care and it has been recommended that dementia befriending services should be increased, yet there are problems with befriender recruitment and attrition. There is little existing research with dementia volunteers and a lack of clarity about factors contributing to recruitment and retention. Research in related fields suggests client work can be both rewarding and challenging, and role definition and professional support regarding emotional experiences are important.

Research into the lived experiences of dementia befrienders is justified at this early stage in order to understand the issues involved in dementia befriending. This could improve understanding of recruitment and attrition issues in dementia befriending, with implications for attracting volunteers to the role and providing any ongoing support they may need.

Research Aim and Question

This study aimed to explore and gain understanding of volunteer befrienders' lived experiences of befriending people with dementia. It therefore addressed the question, "What are volunteer befrienders' experiences of befriending people with dementia?" Whilst research in a broader area has highlighted the importance of role definition and emotional experiences, exploring lived experiences would better allow for these issues to emerge should they be pertinent for this specific group.

Method

Design

This study adopted a qualitative design using Interpretative Phenomenological Analysis (IPA), an approach informed by phenomenology, hermeneutics and idiography. The phenomenological focus is concerned with the examination of a person's lived experience, its meaning for that person and how they make sense of it (Smith, Flowers & Larkin, 2009; Smith & Osborn, 2003). The hermeneutic influence means that the researcher holds an interpretative role in making sense of what is said by the participant (Smith et al., 2009), so a double hermeneutic occurs where the researcher is making sense of the participant who is making sense of their experience

(Smith, 2011). Finally, idiographic approaches are concerned with the particular; thus rather than making claims at the group or population level, IPA focuses on understanding phenomena from the perspective of particular people in a particular context (Smith et al., 2009). IPA therefore met the study aims to explore individual lived experience and was more appropriate than a nomothetic qualitative approach.

The researcher conducted a semi-structured interview with each participant. This is the preferred way of collecting data for an IPA study, as it allows participants to talk about their experiences using their own language (Smith & Osborn, 2003). This participant-led approach is consistent with the phenomenological element of IPA.

Participants

Demographic characteristics. Participants were nine volunteer befrienders from two Age UK Dementia Befriending services. Demographic characteristics are presented in Figure 3. Ethnicity and first language have remained confidential to maintain anonymity. As IPA is primarily concerned with an in-depth analysis of individual experience, it typically requires a concentrated focus on a small number of cases (Smith et al., 2009, 2011).

At the time of the interviews, Harriet was befriending two people and all other participants were befriending one person. Befriendees ranged in age from 66 to 89 years and all had a diagnosis of early stage dementia; this was according to the Age UK service information, as befrienders reported that no medical information was shared with them. See Appendix D for referral process information.

| Pseudonym | Gender | Age | Length of time befriending |
|------------------|---------------|------------|-----------------------------------|
| Alexander | Male | 33 | 2 years 6 months |
| Bill | Male | 66 | 4 years |
| Chris | Male | 65 | 3 years |
| Daphne | Female | 65 | 2 years 8 months |
| Elliott | Male | 30 | 1 year 4 months |
| Fraser | Male | 61 | 4 months |
| Gregory | Male | 25 | 3 years 10 months |
| Harriet | Female | 56 | 4 years 6 months |
| Janie | Female | 26 | 10 weeks |

Figure 3. Demographic characteristics of participants.

Inclusion criteria. Participants met all the following criteria:

- Volunteer (i.e. unpaid).
- Supporting people with a diagnosis of dementia.
- Befriender (i.e. person providing company, support to maintain hobbies and assistance to access the local community).
- Working for an Age UK Dementia Befriending Service (see Appendix D for details). Age UK was an appropriate service as it has been highlighted in several governmental policies as a key initiator in planning and delivering local services (e.g. Audit Commission, 2002).
- Individual face-to-face contact for at least one hour per week.
- At least two 1-hour contacts (for sufficient experience for discussion).

Procedure

Ethical approval. The study design was informed by the British Psychological Society Code of Human Research Ethics (2010), including the core principles, risk, consent, confidentiality and debriefing. The study was approved by Coventry University Research Ethics Committee (Appendix A).

Materials. A demographic questionnaire (Appendix E) was used to gather information about befrienders' gender, age, ethnicity, first language, length of time befriending, number of befriendees and age of befriendees.

The interview schedule (Appendix F) was developed collaboratively with the research team, drawing upon guidance in the literature (Smith & Osborn, 2003; Smith et al., 2009; Hugh-Jones, 2010). It comprised five descriptive, contrast, evaluative and circular questions designed to explore the meaning of the befriender role and the lived experience of dementia befriending. It was piloted by the researcher and another member of the research team prior to interviewing participants; this provided the opportunity to rephrase any questions. In addition, the interview schedule included procedures consistent with IPA methodology regarding informed consent, interview set up, participant debrief and researcher reflexivity.

Recruitment. The Befriending Coordinator at each of the two Age UK Dementia Befriending Services was provided with the information sheet (Appendix E) to distribute to befrienders. Befrienders then opted in to the study, either by contacting the researcher or via their Coordinator.

Interviews. Interviews took place between December 2013 and February 2014. Locations depended on participant preference and included

an Age UK office ($n = 4$), an academic institution ($n = 2$), a public setting ($n = 2$) and the participant's home ($n = 1$).

At the interview, participants were provided with a copy of the information sheet and given the opportunity to ask any questions. They were asked to read and sign the consent form (Appendix E) and complete the demographic questionnaire. The interview procedure was then explained. In particular, the researcher made participants aware that there were no right or wrong answers and likened herself to a naïve, but curious, listener. This reinforced the aim of the research as eliciting participants' understanding of their individual experience, consistent with the phenomenological approach. A semi-structured interview was then conducted as per the interview schedule. Interviews were digitally recorded and lasted between 70 and 120 minutes (average 90 minutes). Following the interview, participants were debriefed and given the opportunity to ask further questions. Finally, the researcher made reflexive notes (see Appendix G), consistent with IPA methodology.

Data Analysis

Procedure. Recordings were transcribed and identifying information was replaced or omitted. Written transcripts were then analysed by the researcher according to IPA, as outlined by Smith, Flowers and Larkin (2009). The researcher kept a written record of each stage of analysis, so that the process can be retraced. See Appendix H for analysis procedures, an extract from a coded transcript and a participant example of analysis.

Validity. IPA is an interpretative methodology and is therefore subjective in nature. One step taken by the researcher to enhance validity was undertaking a bracketing interview with a member of the research team prior to participant interviews. This is part of the phenomenological method and consistent with hermeneutic theory. It helps to highlight the researcher's preconceptions about the topic, so that the researcher is mindful of these during the interview and analysis processes, and focuses on participants' perceptions of the topic (Smith et al., 2009; Thomas & Pollio, 2002).

In addition, an independent IPA researcher analysed one transcript section for comparison and members of the research team reviewed transcripts, preliminary codes and themes. Original transcripts were also constantly referred to throughout the analysis. These processes helped to ensure that the analysis stayed close to the data and was not limited to the lead researcher's perspective.

Furthermore, a reflexive approach was taken throughout the research process, in order to maintain awareness of the ways in which the researcher might influence the study. This was important because the researcher or analyst "brings their fore-conception (prior experiences, assumptions, preconceptions) to the encounter and cannot help but look at any new stimulus in the light of their own prior experience" (Smith et al., 2009, p. 25). The researcher therefore kept reflexive notes throughout the research, which were regularly discussed with the research team (see Appendix G).

Researcher position. The researcher was a female Trainee Clinical Psychologist working in an Older Adult Psychology Service. The researcher had worked with both younger and older adults with dementia, a role that

included frequent contact with local voluntary organisations including Age UK. The researcher also had personal experience of volunteering for several charities. These experiences made the researcher aware of some issues around service provision for people with dementia and mindful that voluntary organisations are an important area for both research and service provision. In addition, the research supervision team comprised three female Clinical Psychologists specialising in mental health, physical health and dementia.

Results

Three main themes encompassed these befrienders' experiences (Figure 4; see Appendix H for theme prevalence). Firstly, befrienders placed their befriendees at the centre of the service and valued befriendees' happiness and individuality. Secondly, befrienders saw the key to befriending as building a relationship with their befriender. This was a special and complex relationship, full of paradoxical intricacies. Befrienders' emotional involvement with their befriendees provided considerable enjoyment, as well as some emotional challenges. Finally, the befriending relationship was powerful. For befrienders, this relationship reconnected befriendees with their identity and community, gave befriendees a sense of freedom, belonging and meaning, and reflected befriendees' humanness.

| | |
|---------------------------------------|---|
| Theme 1: The Person As The Centre | Theme 1a: Putting them first |
| | Theme 1b: Seeing the person past the stereotype |
| | Theme 1c: Valuing the individual |
| Theme 2: A Paradoxical Relationship | Theme 2a: Comparable but indescribable |
| | Theme 2b: Personal but professional |
| | Theme 2c: Two-way but not reciprocal |
| | Theme 2d: Predictable but still uncertain |
| Theme 3: Core Existential Experiences | Theme 3a: Reuniting them with a lost world |
| | Theme 3b: Deeply meaningful experiences |
| | Theme 3c: The essence of human living |

Figure 4. Master table of themes for the group.

Theme 1: The Person As The Centre

Throughout the interviews, all befrienders expressed very strongly that befriending was about making their befriender happy. They were all very clear that their befriender's wishes and wellbeing came before their own; however there were times when all befrienders found this more difficult. They all spoke passionately about seeing their befriender as an individual and the dementia label did not figure in their relationship, despite many befrienders having felt some initial apprehension about the dementia element of their role. There was a shared experience of truly liking befrienders and valuing their individuality.

Theme 1a: Putting them first. The concept of befrienders' happiness was repeated across interviews. All befrienders saw their role primarily as making befrienders happy, so they allowed their befriender to determine what happened in the relationship:

It's more important what's happening for him than what's happening for me, in other words,
let him lead. (Bill, 542-544)

Fraser's befriender enjoyed talking during visits and Fraser 'made sure' he listened, 'even' when his befriender was repeating himself:

It's a positive experience for him in that, you know, he's got someone who's *listening* to him, someone who's interested in what he's *saying*, and I make sure I *am* listening to what he's saying, even if he's said it several times already. (849-852)

Befriending therefore meant putting the befriender first, but as Fraser's account implied, most befrienders found this hard at times. Most commonly, befrienders found the predictability of the visits tiring, suggesting visits could be emotionally draining. Some befrienders experienced unfamiliar situations where they felt out of their depth and unsure how to respond. For other befrienders, there was a sense of guilt and anxiety that they were not doing enough for their befriender. Their role was not without its 'pain', as Alexander explained:

I know that the way I'm putting it sounds a bit like I'm hating it [pause] but that's the truth that it's hard [...] it's not all kind of like jolly happy volunteering, big satisfaction no pain. (371-374)

Some befrienders found it easier when their personal values could influence the visits. Central to Elliott's account was the importance of his befriender setting goals and having achievements, but he acknowledged that this purposeful approach 'works' for him as a befriender:

I'm very goal-oriented, and I think it works better, for *me*, if I can say this is what we've tried to achieve, and if we can look back and say [...] we've come a long way. (147-150)

His account reflected a shared desire amongst befrienders to make a difference to their befriended. When befriended appeared happy, it seemed to reassure befrienders that it was worthwhile to put their befriended first.

Many befrienders talked about the influence of their mindset in coping with the emotional challenges of the befriending role. They perceived any difficult emotions as an inevitable part of the role and therefore saw themselves as responsible for managing those emotions. Daphne expressed this clearly:

It's only tiring *if* I let it be, if I'm in the wrong mood, and that's down to me. Because he *is* constant. He's *exactly* the same every week [pause] and if I let that get to me then that's *my* problem, it's not him. (772-774)

This reflected befrienders' commitment to their role and to their befriended. Although the emotional challenges meant that some befrienders questioned their ability to 'go on' at times, they continued because of the value they placed on their befriended's happiness, as Chris' account illustrated:

I've said a couple of times, I'm so bored now I don't think I can go on, but he obviously *misses* me when I don't go [pause] and I *know* he can't talk to his daughter the same way. (244-246)

Thus, while it was difficult for befrienders at times, their befriended's happiness came first.

Theme 1b: Seeing the person past the stereotype. All befrienders emphasised that befriendees were people in their own right, with individual traits, strengths and values, as opposed to being a person with dementia. Fraser highlighted the valued roles that his befriender still had, irrespective of dementia:

He's still somebody's dad he's still somebody's granddad he's still somebody's
great-granddad he's still somebody's friend. (564-565)

Befriending was described as a process of getting to know the person, in contrast to many befrienders' initial apprehension and uncertainty about the dementia element of their role. Many acknowledged that befriending had challenged their own preconceptions about dementia. Gregory remarked, 'those stereotypes get broken down straightaway' (line 40-41), suggesting that stereotypes could act as a barrier in the relationship. Befrienders did share concern that the dementia label deterred others people from taking on the befriending role. As Harriet expressed with warmth and passion:

It's lovely, you know, if anyone was thinking about doing it I'd just sort of say to them,
"do you like *people*?" Really, it's not people with dementia it's *people*. (621-623)

The concept of befriendees being people was particularly important to Bill. Like Harriet, he commented that he often forgot his befriender had dementia because their relationship was 'bouncing along normally' (line 432). In contrast, he felt that wider society was quick to label people with conditions such as dementia, learning disability and cancer, and he expressed

frustration about society 'thinking of people as freaks' (line 599-600). His befriender was a person, not a label:

I'm not going along to befriend somebody who has Alzheimer's,
I'm just going along to see Liam. (465-466)

Janie also felt frustrated that people with dementia were stereotyped. For her, this took away people's individuality and implied they were less able than they actually were:

I think people are too quick to just, you know "*that's* the way you think, you've got dementia we'll just have a very nice basic conversation with you" [...] I think she *does* deserve more than that and she can *cope* with more than that. (250-255)

For befrienders there seemed to be a stigma associated with dementia that affected how befriendees were treated by others, and many befrienders expressed wanting to let people know that this was wrong. Befriendees were people and individuals, and befriending meant enabling them to express their individuality.

Theme 1c: Valuing the individual. All befrienders expressed liking and valuing befriendees' personal qualities, to varying degrees. There was shared positive regard for befriendees, who were described as interesting, intelligent and capable people:

He's a nice old man [...] I don't really feel sorry for him, because he is intelligent and he's capable [...] he's been an interesting person to know, and I can think of an awful lot of people that I've met that I've liked an awful lot less. (Chris, 867-874).

Rather than pity his befriender, Chris saw and liked his befriender's strengths and abilities. Similarly Harriet saw her befrienders as 'fascinating' people, often with unusual jobs or backgrounds (line 262). For Alexander, his befriender's character made his befriender 'worth' visiting:

I feel like it's important that I go and visit him because he's worth it [...] he's worth my attention, my visit, because he's not a you know he's not a trivial character. (646-651)

His account suggested that his high regard for his befriender acted as a means of motivation. For Daphne, appreciating her befriender's strengths enabled her to 'genuinely' respond to him:

He's *much* more knowledgeable than I am. He remembers better than I do [pause] and he's got a wider range I think than I have, and that's good because I can *genuinely* sort of say great, well done, remembered. (687-689)

Daphne's account contained a sense of admiration and respect for her befriender, which other befrienders also conveyed during interviews; for example Elliott expressed appreciation of his befriender's courage when finding situations 'difficult' (line 287). Similarly, Gregory's account centred around taking advice and learning from his befriender, particularly about love and relationships. He explained that this influenced decisions in his own relationships and he once brought his wife to meet his befriender:

I wanted her, kind of like her approval [...] I was really nervous that Norah would like [my wife] [...] and I wanted [my wife] to like Norah as well. (639-642)

His account illustrated the extent to which he valued his befriender. While this varied amongst befrienders, there was shared appreciation of befriender's personal and unique characteristics.

Theme 2: A Paradoxical Relationship

The relationship between befriender and befriender was the foundation of befriending. It was special yet complex, containing four paradoxical processes.

Theme 2a: Comparable but indescribable. As Gregory expressed, it felt almost 'impossible' for any befriender to satisfactorily describe their relationship with their befriender (line 388). The qualities of the relationship made it both like and unlike other relationships, so words used to describe other relationships did not seem to fit. This often left the befrienders at a loss for words, as Elliott found:

It's not like a relationship I would have with a friend, it's not a kind of relationship I would have within the family [pause] I mean it's certainly professional in a way [...]
I can't really explain that kind of relationship. (519-524)

Furthermore, befrienders and befriender took a multitude of roles within the relationship. This made it difficult to describe their relationship in a single word and indicated that they played a unique role in each others' lives. To their befriender, befrienders functioned as carers, friends, lunch buddies and confidantes. Befrienders likened their befriender to parents, grandparents, partners, friends or educators, as conveyed during interviews by their language and tone of voice. The closest likeness was a friend,

despite this not being a totally satisfactory descriptor; the exception was Daphne, who described her befriender as her friend several times.

Befriending meant giving time, patience and attention that befriendeds often did not get from others:

I'm the only person that goes to see him that he can tell this story to every week, that keeps his old self alive. (Chris, 833-834)

The befriender role provided a unique space for befriendeds to be themselves, and to maintain an identity that was otherwise lost. It was clear that this was of great value to their befriendeds, as Janie described:

Her eyes light up and the idea that *she's* got a visitor *just* for her just to come and talk to *her* and take an interest in her, you sort of get a sense that this is actually really unusual. (83-85)

The fact that Janie mentioned a 'sense' also indicated something intuitive about the relationship, which may partly explain its indescribable nature. It seemed to have an intangible and indefinable quality, which several other befrienders mentioned. For example, Gregory highlighted that there was an element of 'chance' in the befriending relationship, that befriending was based on 'random' matching of befriender and befriended, and that their feelings for each other depended on the 'chemistry' between them (lines 676-687). The befriending relationship therefore seemed a complex one. For befrienders, it had some but not all qualities of any other relationship, which made it comparable but indescribable.

Theme 2b: Personal but professional. The befriending relationship involved a unique blend of personal and professional qualities. Befrienders expressed the personal element of the relationship very strongly during interviews, although the extent of their emotional closeness with befriendees differed. For Elliott, a ‘nice vibe’ was sufficient:

There’s a nice vibe, it doesn’t have to be like a close trusting kind of friendship,
it’s just a nice pleasant relaxed relationship. (513-514)

Other befrienders shared parts of their personal life with their befriender; for example Bill jokingly described his befriender as a counsellor. This sharing of personal topics meant that their relationship could feel quite ‘intimate’ as Harriet described:

She could tell me that she had the diarrhoea, that she was worried about it, what was happening [...] and to *me* that feels intimate, you know, *sharing* those sort of things, sharing some of the things she’s told me about family life [...] they’re just not things that, I’d expect someone would be telling you unless they really trusted you. (662-668)

Several befrienders voiced reluctance to articulate love, but many expressed feelings of love in the way they spoke about being there ‘unconditionally’ (Alexander, line 472), ‘treasuring’ their befriender (Bill, line 681), feeling ‘uplifted’ (Elliott, line 221) and feeling ‘blessed to have her in my life’ (Harriet, line 164). Gregory was one of the befrienders who felt most able to articulate his loving befriending experience:

I felt very close to her [...] I think it's a strong word but I think there were elements of love there, definitely, in the relationship, cos I cared for her, and she was fond of the time we had together [...] it was an amazing experience, and a really beautiful relationship. (456-460)

Rather than suggesting that he liked his befriender, as discussed in Theme 1c, his account suggested shared feelings of closeness and caring in the relationship between befriender and befriender. For some befrienders, this was contrary to their expectations of the befriending relationship. Daphne anticipated providing a service, which implies a lack of emotional attachment:

They'll probably give me an older retired woman and I can go and do her shopping, and go round and perhaps *read* to her or something like that, that was the *sort* of thing I had in mind when it started off. (53-56)

Thus all befrienders' preconceptions about dementia, and the meaning of befriending, changed as they got to know their befriender. They found that they developed a genuine and caring relationship with their befriender, which made befriending easier and more enjoyable for them.

Indeed, a lack of shared emotional and personal experience caused some significant difficulties for the befriender. Chris felt that his befriender was 'self-censoring' during their visits, in that his befriender chose to reveal little about himself, and as a result Chris felt like 'a stranger to him' (lines 180-183). This had a considerable negative impact on their relationship:

He's just regarding me as some kind of [servant] [...] like some kind of lower-order being that's been brought in to provide a service for him that he requires and, beyond being *polite* [pause] he doesn't have to deal with me as a person and that made me angry. (231-235)

The lack of emotional closeness made Chris feel depersonalised, even dehumanised. Indeed when asked to describe his relationship with his befriender, he replied, 'it's mechanical' (line 274), indicating an absence of human emotion and connection with his befriender. This made him question whether he could continue the relationship. His account suggested that emotional and personal closeness was an important element of the befriending relationship that made it enjoyable for befrienders.

For some befrienders, however, their caring feelings for their befriender raised the poignant issue of their befriender's death. This was seen as an inevitable issue because of their befriender's age and physical health, not just the dementia. Several befrienders spoke about their 'fear' of their befriender dying:

My biggest fear, probably, is that, if he dies on me [...] that's my biggest fear, after having built this relationship then I lose him. (Alexander, 732-734)

Alexander's repeated description of his befriender's death as his 'biggest fear' emphasised how much he cared about his befriender. Similarly, other befrienders spoke emotively about befrienders who died:

It's difficult to reflect on it [...] I don't think I'm fully, like, able to detach myself, objectively, and say like this is what she meant to me because I still feel a bit, even maybe I shouldn't I don't know, but I do feel a little bit of guilt there still, that I didn't do more for her [...] if I could have in any way made her life better, then I'm really happy about that, and that's a huge life experience that I won't forget, and I'll always cherish. (Gregory, 430-488)

Befrienders' accounts illustrated the intensity of the emotional challenges that they could experience and reflected befriendees' personal significance.

In contrast with the personal relationship was befrienders' professional position. Many befrienders identified themselves as being an Age UK worker and saw their role as a commitment. It was a multi-faceted role that involved planning outings, liaising with their befriender's family and signposting to local services. Befrienders also felt a sense of responsibility for their befriender and wanted to 'look after them properly', as Fraser explained:

There's an element of sort of being his carer if you like, and when I get back to the house, I always make sure he's actually settled in properly, you know, I don't just leave him at the door or anything [...] [it's] making sure he's looked after properly in the time I'm with him.

(307-312)

Befrienders saw their befriender as being in their care during visits. While this professional responsibility felt manageable for most other befrienders, for Alexander the enormity of this meant that he felt unable to take his befriender out of the house:

Once we are outside a safe environment I am his only port of call, right it's only me, there is no lady to help him out from I mean the carers at the house [pause] that's a bit scary for me.

(726-729)

His words indicated a sense of danger about being a lone worker and several befrienders did speak about feeling isolated and anxious, particularly in comparison with their paid jobs. Alexander also contrasted his role with

that of a professional carer, perhaps implying that he wanted to feel more knowledgeable and competent before taking his befriender out of the house. Indeed, many befrienders felt it was important that they knew what to do in a given situation and described their befriending experience as a 'learning curve' (Janie, line 182). Thus the befriender role comprised a blend of personal and professional elements, which was one of the paradoxes making the befriending relationship special and complex.

Theme 2c: Two-way but not reciprocal. The befriending relationship was often described as two-way, but neither reciprocal nor equal. Most befrienders felt that their relationship with their befriender was two-way, in that both befriender and befriender contributed to and benefited from the relationship. There were numerous caveats to this, however. For example, befriender and befriender tended to 'get very different things' from the relationship (Harriet, line 1115), there was imbalance as 'he does more of the talking than I do' (Fraser, line 363), and there was a difference between theory and practice: 'it *is* a two-way process but it's not really a two-way process' (Chris, lines 654-655). Indeed for Alexander, the relationship's one-way nature was what set it apart from 'real' friendship:

For me a friend in the real world is somebody who I can give something to and they give something back to me [...] that is not the case here I can't say Winston you know what I got fired help me out you know it's not that sort of relationship [...] befriending is it's a real one-way thing, I am befriending *him*, it's not a two-way thing. (229-234)

This suggested that the professional element of the role, as discussed in Theme 2b, had a significant influence in defining the befriending relationship.

It may have contributed to a power imbalance in the relationship, as illustrated by Chris' account:

He really wants to talk about these things he *really* wants to tell me this story again, and, I'm nice enough to let him do it, and then if I get really bored I'll take something out of him for, you know payment for that, I'll make him listen to something he doesn't want to listen to or something [laughs] and then we're quits. (746-750)

The concepts of 'letting', 'taking' and being 'quits' in his account suggested a possible ongoing power imbalance between befriender and befriended. Indeed, there was a shared sense amongst befrienders that the relationship was unequal. Many befrienders expressed that equality was very important and some like Bill consciously developed ways in which their befriended could give to them, such as seeking their advice. Several befrienders like Daphne highlighted humour and teasing as a reflection of equality between befriender and befriended. Ultimately, however, befrienders' professional capacity as discussed in Theme 2b meant that they typically led the visits; for example Gregory supported his befriended to relearn skills, Elliott organised outings, and both Fraser and Janie described steering the conversation to enable befriendeds to participate. To an extent, befrienders expected this to be part of the role and thus accepted the imbalance. At times, they were even able to use it to their advantage, such as choosing to put their befriended first or negotiating a relationship that felt comfortable for both befriender and befriended. Fundamentally though, they disliked having more power than their befriended and valued times when it would 'feel' equal:

Although I say I have a back and forth and it feels like I have an equal conversation with Nellie, it is *just* in the moment those glimpses of it [...] for five minutes it'll feel like an equal relationship and then it'll go back to me leading the conversation, and I value those five and that's what I kind of take away from it, those are the memories I have but in reality I *am* leading it. (Janie, 1039-1044)

Equality and reciprocity therefore seemed to function as signs of a natural relationship, as reflected in Chris' earlier description of feeling angry about being regarded as a 'lower-order being'. His earlier account of taking 'payment' also indicated a sense of anger and retaliation, which reflected a shared need amongst befrienders to gain something in return for putting befriendees first (as discussed in Theme 1a). Daphne said that she and her befriender developed a 'modus vivendi', which she described as:

The way of living together. Or it could be modus operandi the way of operating together.
You know, we've found a way of making it work. (821-822)

For befriending to truly 'work', befrienders needed some reciprocity.

Theme 2d: Predictable but still uncertain. Many befrienders spoke about predictability in their visits with their befriender as a result of the dementia. Some experienced repetitive conversation:

It was almost like a scripted conversation [...] as we went through the weeks I knew I would be prompting him to say the next thing in the chain. (Chris, 35-40)

Other befrienders like Fraser found that a particular topic of conversation would 'stick' for the duration of a visit. As he explained, it felt futile to try and change topic because befriendees were not cognitively able to do this:

We tend to get a topic of conversation comes up [...] and that topic of conversation *tends* to sustain us if you like for that visit, and even if you try to move *away* from that, to something else, you find that he tends to come back to that particular topic, because he's got that in his *mind*, and therefore that will stick. (232-237)

As befrienders put their befriender's happiness first, there came a sense of inevitability and acceptance from befrienders. Variety was seen as rare and they tended to become part of their befriender's 'script'.

In contrast to this predictability, many befrienders experienced uncertainty in terms of not knowing whether they were making a difference to their befriender. Some befrienders saw their role as slowing the progression of befriendees' dementia, but they also conveyed a sense that this was idealistic, as illustrated by Chris' account:

The *only* person he can just let these things loose to is *me*. So I think I *do perform* a service for him, whether it's helping his condition [laughs] I don't know. (251-253)

For them, befriending meant giving their befriendees someone to talk to, confide in and express themselves with. This felt important on a personal and human level for befrienders, but there remained a shared sense that the longer-term impact of this was debatable, as Fraser explained:

I don't *know*, in all honesty, I don't *know* [pause] erm what good I'm doing him in my visits, all I know is when I *go*, he smiles [...] he's *obviously* happy to see me and he always says thank you when I go so I have *confidence* that he's pleased to see me [...] but hand on heart, I don't know how much, erm, good the visit does, other than break up his routine. (119-125)

Thus befrienders valued 'evidence' (Bill, line 671) of their impact on befriendees. Positive feedback from befriendees' family and their Befriending Coordinator was particularly encouraging. Sometimes befrienders took 'no complaints' (Daphne, line 829) as a sign to continue visiting. Primarily, though, befrienders relied upon their befriender's response to their visit:

It's hard cos you can't really measure it with anything, whether it's had an impact on her mentally kind of long-term [...] all I can tell is you know she's interested, she's engaged and she's enjoying it so [pause] just keep doing it. (Janie, 309-314)

In addition to the uncertainty of the long-term impact of befriending, some befrienders felt uncertain about the future for them and their befriender. They acknowledged some gradual changes in befriendees' abilities, mood and behaviour that reflected progressive deterioration, characteristic of dementia. However, they were not always particularly conscious of these changes, as Bill explained:

I think something will happen when it *does* impact on me, if we continue to if he *does* have Alzheimer's and it continues as I believe it's supposed to, a time will come when I *do* feel about it differently but it hasn't come yet [pause] because it's still pretty, on many levels, as it's always been. (545-549)

His account captured both the predictability and uncertainty about the relationship, the diagnosis and the future. This reflected the fourth paradox in the befriending relationship.

Theme 3: Core Existential Experiences

Despite questioning the benefits of befriending, befrienders spoke in emotive ways about the deep and meaningful gains they felt their befriendees took from their visits. For them, befriending enabled their befriendees to reconnect with their own identity, as well as with their community, which was often lost through isolation rather than through dementia itself. Many befrienders expressed the importance of befriendees knowing that they matter and having freedom, independence and meaning in their lives. At its most core, befriending satisfied a fundamental human need for social connectedness and stimulation, and represented the meaning of being alive instead of just surviving.

Theme 3a: Reuniting them with a lost world. Befrienders spoke in moving terms about their befriender's intense isolation and loneliness. This meant that their befriender often lost their identity, their contact with their community, and their touch with the world itself:

When you have dementia, I think [...] you can feel separate from *everything* [...] your own experiences, mind, ideas, and what you used to be like, and everything [pause] as well as more widely like with people community family. (Gregory, 421-425)

Out of this came a sense that befriendees could feel cut off from who they were and what was happening around them. Befrienders shared a profound

sadness about this. It was therefore particularly powerful when befrienders described how the befriending relationship enabled their befriender to reconnect with their own identity, by bringing closer the things that truly mattered to them:

We went a couple of times to down to the computer, and we put Laurence Olivier on YouTube, stuff like his favourite scene, and he played it again and again and again and at some points he was repeating it and he stood up and he started, then he started crying and then he said “hey can we put more things” and he he and he couldn’t believe that I could operate that machine and knowing that I could operate it it’s amazing like videos of Laurence Olivier are online there’s the clip he was amazed he was like wow [...] he was so happy.

(Alexander, 379-387)

For Alexander, he was doing something relatively simple for his befriender, and yet it was evident from his befriender’s amazement and tears that the experience was incredibly meaningful.

In addition to reconnecting with their sense of self through simple activities, befrienders rediscovered their community when they went out with their befriender. Their regular visits meant that they became known by staff or other members of the community, which led to friendly conversations:

She *likes* where we go, and they know us now and it’s “do you want your usual?” when we go through the door. (Harriet, 135-136)

Daphne gave an empathic explanation of why this was so important:

I'm sure if I was housebound, the only thing I would want to do is get out in the fresh air, and you know, go into a shop and feel part of the *wider* human race, you know go and *buy* something and *talk* to somebody, and *have* that interaction which you know, means you're part of the community. (189-193)

In the same way that Elliott felt familiarity gave befriendees 'a sense of belonging' (line 811), Daphne's account suggested that active community involvement made befriendees feel like a resident in the community instead of an outsider. For her, it also signified befriendees' very humanness.

Theme 3b: Deeply meaningful experiences. Befriending signified some very meaningful experiences for befrienders. Several spoke about the importance of giving their befriendees choice, control and independence. This contrasted with befriendees' metaphorical 'prison' (Alexander, line 15) and there was a strong sense of freedom in the way that befriending visits were described during interviews. For example, Harriet described a time when she and her befriender 'broke out' of hospital and went to a cafe together (line 185), Alexander wanted his befriender to 'feel free' to do whatever his befriender wanted during visits (line 519), and Chris felt that his visits gave his befriendees an 'opportunity to let loose' (line 103).

Like some other befrienders, Harriet also spoke empathically about wanting befriendees to feel 'safe' and 'cared for' (line 923), echoing the concept of valuing befriendees. Befriending also provided rare opportunities to show befriendees that they matter. Fraser recalled a time when he and his befriender were eating at a place his befriender used to go regularly, and one of the long-term staff came over to talk to his befriender. She recalled many details about him, such as who he used to go with and what he used to

order. Fraser described this as a 'powerful' and 'affirming' experience for his befriender (lines 67 and 77). When asked why, he replied:

To know that you know, there's someone who obviously takes an *interest* in him, erm, was pleased to see him and remembered all *about* him and so on and so forth [...] it gave him that reassurance that, that he *meant* something to someone. (103-107)

Fraser's account indicated that having acknowledgement from others validates a sense of self. Thus, through this interaction, Fraser's befriender felt valued by others. Befrienders' ability to contribute to others' lives gave them 'a sense of purpose', as Janie described:

I think it goes back to you know a sense of *purpose*... that she's got something to contribute she's got stories that other people are interested in, she can offer the advice she can *do* something. (93-97)

This seemed to mirror the experience of befrienders, who felt that they had more purpose when they were making a difference to others. This reinforced the human element of befriending, in that there was no difference between the human needs of befrienders and befrienders alike.

Theme 3c: The essence of human living. When befrienders spoke about the meaning of befriending, they expressed a powerful and profound account of what it means to be human and alive. Many befrienders described it as a fundamental human need to build relationships, to have friendship and to share experiences with other people. They emphasised that this was

nothing to do with dementia but that as human beings, we all share a need for company and closeness. This was particularly important for Alexander:

I think that's only natural, to to be more alive when you have company around you [...] you don't have to be him locked in your flat with dementia to be like that I think every human being is like that [...] you need a social [pause] a social context around you to to be a human being to be alive. (284-289)

The befriending relationship therefore represented an essential human experience. Chris described what this meant for him:

There's just [pause] feeling the warmth of other people [...] knowing that you're two human beings, that understand each other and are [pause] trying to be nice to each other, and helping each other out a little bit. (630-634)

For befrienders, their befriendees were fellow human beings. Indeed, in contrast with his earlier emphasis on goals, Elliott's fondest memory of his time with his befriender was when they went for a long walk and just had 'quality time' together:

It didn't feel like we were trying to do anything [...] just having a pleasant conversation, just enjoying the walk, sharing a couple of jokes [...] there aren't many times when there are people with him but they're not doing anything for him [...] it's just to have that quality time. (551-559)

Befriending was conveyed as experiential, a time when two people could just *be* together.

In addition to being an experience of humanness, befriending was described as an experience of living and being alive. Many befrienders like Bill talked about the importance of the visits having energy, and of befriendees being able to move around and actively participate in activities and social interaction. For Harriet, this conscious awareness and engagement was the meaning of being alive:

These days it's very *easy* to get people to the point where they are *surviving*, you know, they're breathing and all their physical bits are, are working, if you like, so, so being alive is more [pause] about having experiences and, and having [pause] having relationships and, and meeting people and doing things. (1385-1389)

Befriending was personal, emotional and experiential, and this signified the very essence of humanity and living. Throughout the interviews, it was clear that befriending was an indescribable, special and complex phenomenon. For befrienders, it represented deep and core human experiences.

Discussion

For this group of dementia befrienders, their experiences centred on their befriender: as a unique individual, as a person they cared about, and as a fellow human being. For them, befriending meant developing a relationship that enabled befriendees to reconnect with their individuality, community and humanity. The befriending relationship comprised numerous paradoxical processes that generated difficult issues of reciprocity, power and uncertainty. These added to the emotional challenges of befriending, which included tiredness and anxiety, and characterised befriending as a complex and unique phenomenon.

Befrienders' focus on their befriendees' happiness in Theme 1 was consistent with elements of the person-centred approach, a model often cited in dementia care. Defining elements of this approach include honouring individual values, offering choices and unconditional positive regard (see Edvardsson, Winblad, & Sandman, 2008 and Love & Pinkowitz, 2013). These elements are reflected in dementia policies and care models such as VIPS: Valuing people with dementia, treating people as Individuals, using the Perspective of the person with dementia, and a positive Social environment (Brooker, 2007; Department of Health, 2009, 2012; NICE, 2006).

The person-centred approach was influenced by Kitwood's (1997) concept of personhood, which 'implies a standing or status that is accorded by others' (p. 4). It requires true recognition of the other as a person, as opposed to treating people as objects; thus person-centred care means interactions and relationships that support the self (Fazio, 2013). Indeed in research interviews, people with dementia highlighted that promoting a continuation of self and normality was fundamental to their wellbeing (Edvardsson, Fetherstonhaugh, & Nay, 2010). Befrienders echoed this in their emphasis on reconnecting befriendees with their identity and community. Furthermore, befrienders' emphasis on the importance of their relationship with their befriender in Theme 2 was consistent with the concept of personhood as relational.

The current findings highlighted the significance of the relationship in the experience of dementia befriending, with three particular aspects. Firstly, the value of closeness between befriender and befriender, and of having a personal element to the relationship, suggests that matching befrienders and

befriendees is an important part of befrienders' experiences. Indeed, Dean and Goodlad (1998) described the matching process as crucial to success in befriending. Secondly, the complexity within the befriending relationship for these befrienders was closely related to a) experiences of other sector befrienders, b) descriptions of friendship by people with dementia, and c) characteristics of a therapeutic relationship (e.g. Dean & Goodlad, 1998; Elvins & Green 2008; Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003; Sabat & Lee, 2011). For befrienders in this study, this complexity was part of their lived experience of the befriending relationship. Finally, befrienders' experiences of emotional challenges within the relationship related to some experiences of other volunteers who expressed feeling demotivated and discouraged, particularly when they felt ineffective (e.g. King et al., 2009; Kristiansen et al., 2006; Rath, 2008). Befrienders' uncertainty about their impact on befriendees, and on the dementia process, was part of their lived experience of befriending. It relates to operant conditioning, a behavioural learning process whereby the consequences of an action determine the likelihood of that action reoccurring (Fisher, Piazza, & Roane, 2011). Specifically, positive reinforcement or a favourable outcome makes an action more likely to occur, and absence of reinforcement makes an action less likely to occur (Fisher et al., 2011). Thus, for befrienders to continue their befriending relationship suggests that the gains outweigh the challenges.

Fundamentally, these befrienders felt that the meaning of befriending related to core existential experiences, as in Theme 3. Indeed, according to existential theories, psychological wellbeing is affected by ultimate concerns including meaning, freedom and relationships (Jurica, Barenz, Shim,

Graham, & Steger, 2014). The importance of these issues is supported by recent research; for example having greater existential meaning reportedly a) protects against suicidal ideation, b) predicts increased hope and decreased depression, and c) moderates psychotherapy outcome (Heisel & Flett, 2014; Mascaro, 2014; Shadrin, 2013).

Furthermore, person-centred approaches are based on humanistic principles, specifically that people are multi-dimensional beings and that psychosocial, spiritual and physical elements hold equal importance for holistic wellbeing (Rogers, 1980, as cited in Love & Pinkowitz, 2013). In particular, desires for emotional closeness and autonomy are considered two primary human instincts that directly nurture wellbeing (e.g. Deci & Ryan, 2000; Pederson, 2004). In addition, belonging, esteem and self-actualisation have been identified as basic human needs (Maslow, 1970, as cited in Thielke et al., 2012). Research has shown the satisfaction of such needs to be associated with basic human motivation and a variety of long-term positive outcomes across cultures; these include wellbeing, adaptive psychological functioning, health behaviour change and even a longer life span (see Schöler, Brandstätter, & Sheldon, 2013, and Sheldon & Gunz, 2009). The Dementia Initiative's Person-Centred Dementia Care Framework highlights that the ways of interacting that support a person's unique preferences and needs "help a person to feel human and convey that they have worth and value" (Love & Pinkowitz, 2013, p. 27). Thus, befrienders' emphasis on befriendees' sense of purpose, value and belonging, and their focus on the relationship and sense of closeness, are all consistent with satisfaction of human needs.

Clinical Implications

Befrienders' emphasis on the personal element of the befriending relationship indicates the importance of the matching process. Findings suggest the value of a thoughtful and considered approach to matching.

The concept of making a difference was particularly significant in befrienders' emotional experiences of befriending. Findings regarding the complexity of the befriending relationship and the existential meaning of this for befriendees could inform future training, supervision and ongoing support. Aims could include a) helping befrienders to maintain realistic expectations of their role, b) validating the short-term effects of their visit on befriendees as well as any longer-term effects, and c) normalising their emotional experiences. In addition, it may help befrienders in their expectations for the relationship to have greater knowledge of the wide variety of cognitive deficits in dementia. These include cognitive flexibility, attention, information processing, reasoning and planning (e.g. Qizilbash et al., 2001).

Befrienders' effectiveness could be assessed in terms of befriendees' sense of belonging and being a valued part of community life. This was one of seven outcomes that people with dementia and their families would like to see in their lives, according to the National Dementia Declaration 2010 (Dementia Action Alliance, 2014). This could be added to other outcomes of befriending including loneliness, worry and self-esteem (Windle et al., 2011).

Publicising befrienders' experiences of the personal and human aspects of befriending could help to address the stigma around dementia, which many befrienders acknowledged themselves. For example, promoting the current findings on the Age UK website could potentially assist

recruitment of future dementia befrienders. More generally, given the perceived importance of genuine and person-centred relationships for people with dementia, other workers such as care staff could be supported to develop such relationships with their clients.

Limitations

Results cannot be generalised to all dementia befrienders and should be considered suggestive rather than conclusive. As with other qualitative studies, the sample size was relatively small and while similar themes were identified amongst these participants, other themes could arguably have emerged from other participants. The sample was also self-selecting and befrienders' motives for participating could have influenced the topics discussed. In addition, the age range of the sample was relatively large and could be considered to affect homogeneity, although participants' experiences did not appear to differ significantly according to age, as reflected in theme prevalence (see Appendix H). Such diversity in age could therefore be indicative of the universality of befriending.

Another potentially influencing factor was that during recruitment, the researcher explained that this was the first study of dementia befrienders' experience. This may have prompted befrienders to talk about the more positive aspects of befriending in order to 'sell' it. It is argued, however, that all participants acknowledged challenges in befriending, suggesting they were not exaggerating a positive presentation of themselves or befriending.

Furthermore, IPA is a subjective methodology and while efforts were made to enhance validity, it is acknowledged that findings are not objective. Interactions between participant and researcher will have impacted on the findings. The majority of participants were male and may have responded differently to a female than a male researcher. The researcher also noted discussion of psychology study and practice during one interview, which was more likely given that the researcher was a Trainee Clinical Psychologist.

Suggestions for Future Research

Detailed investigation of effective befriending relationships could show that this voluntary sector service may offer a richly emotional and effective intervention beyond what is possible within current NHS budget and provision. It is therefore recommended that future research considers issues including effectiveness, attrition and support.

It is suggested that future research explores befriender and befriender perceptions of what makes a 'good match' in the befriending relationship. This could enhance understanding of effectiveness and inform future development of community-based dementia care.

Research with people who discontinued befriending is also suggested, to gain insight into specific challenges of dementia befriending. This has potential implications for improved support and retention of dementia befrienders. Using current findings to develop online questionnaires may enable wider-reaching investigation of befrienders' experiences.

Finally, given the importance of emotional and personal closeness in many of these befriending relationships as well as the progressive nature of dementia, future research could explore a) dementia befrienders' experiences of bereavement and coping, and b) befrienders' understanding of their role in relation to dementia and its progress. This could help to improve befriender support and to inform training regarding realistic expectations of dementia befriending.

Conclusion

The notion of the person emerged in this study as an important aspect of volunteers' experiences of befriending people with dementia. Befrienders did not see a dementia label, but instead saw a person with individual strengths and abilities. They genuinely cared about this person and valued their relationship, despite its paradoxical difficulties and emotional challenges. Befriending meant enabling befriendees to express their individuality, reconnect with their community and know that they have worth and meaning. For these befrienders, this was the essence of being human and alive.

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Chapter 3: Reflective Paper

Reflections on Boundaries in Clinical Psychology: Choosing When to Adapt or be Adaptable.

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Reflections on Overcoming Boundaries in Clinical Psychology: When to Adapt and When to Be Adaptable.

Overview

While conducting my doctoral research, I noticed some boundaries that I found helpful, and some that I experienced as challenging. The challenge for me was in knowing when to take control and adapt something that was already there, and when to acknowledge limitations and be adaptable myself. In writing my literature review, this was a key question I ended up asking: should we be adapting therapy for older people, or should we be adaptable to the individual?

This reflective account summarises the helpful and challenging boundaries that I experienced in conducting my doctoral research. Having investigated and questioned cognitive-behavioural therapy in the first two papers of this thesis, I present some thoughts on the process of adaptation from an alternative perspective: Personal Construct Psychology. I worked from this approach during my specialist clinical placement, and it helped me to further develop my psychological skills of assessment, formulation and reflection; all of which are important in preparing this reflective account.

Helpful Boundaries

Some of the helpful boundaries were those that I put in place for the duration of my research to help me cope better. For example, I adapted one room in my house to make it a study, as I found that working in any other

rooms made it difficult for me to rest and relax. I would often shut the door when I finished working, as this helped to clarify the boundary between working and relaxing, and to change my mindset accordingly. This is one of the reasons I think it is helpful for organisations to provide a separate staff room, to enable staff to take proper breaks. Physical boundaries translate into emotional containment, so the office contains work-related stresses and physically moving away from those helps to emotionally move away.

I also found that having a clean and tidy workspace helps me to be productive. When my study is cluttered, I tend to feel agitated and find it more difficult to concentrate than when it is tidy. Working in an ordered environment enhances my mood and my productivity. I think this applies in the workplace too; I believe there is a need for organisations to promote a clean and tidy working environment, in order to support purposeful and good quality work. These ideas about the impact of the working environment are supported by research; for example it is reported that inappropriate environmental conditions can negatively affect the success of supervision (Gilmore, 2001), and that the working environment affects quality of patient care, patient and staff wellbeing, and the productivity of NHS Trusts (West, Dawson, Admasachew, & Topakas, 2011).

These boundaries seem to provide clarity through their structure. This made me think about the structure of therapy, and how this is important in clarifying what therapy is, and distinguishing therapy from “a chat”. For example, therapy involves regular and time-limited sessions. These are based on psychological theory, and are goal-oriented, to a greater or lesser degree depending on the approach. ‘Homework’ in some form is common,

whether as a behavioural or reflective activity. In addition to these types of structures, there are other boundaries in therapy that differentiate it from everyday conversation. For example, the therapist tends not to share much personal information with the client, whereas in everyday conversation, it is common for all parties to share information about themselves.

These ideas make me think about my literature review. Structure and boundaries must contribute to making therapy helpful; otherwise everyday conversation would have a similar effect. If structure and boundaries are helpful, it is understandable for authors to suggest making therapy even more structured to enhance outcomes with older adults. The findings did not necessarily support this, though, so there may be a point at which boundaries and structure stop being helpful or even feel challenging.

Challenging Boundaries

I needed to gain approval to conduct my research from a committee, but I encountered some inflexible boundaries in this process. The committee raised methodological concerns about my research proposal, specifically around the randomisation of participants to treatment conditions. I found it a challenging and frustrating process to resolve these concerns.

Part of my frustration was that the solution was not within my control, as it was proposed by the committee and their boundaries could not be negotiated. This meant there was little I could do, which left me feeling powerless. Supervision was particularly helpful for me at that time in containing my frustrations.

This experience makes me wonder, though, what happens when clients find therapeutic boundaries challenging. There may be times when they feel powerless, for example if the number of sessions is limited. I wonder how clients cope with this, and whether they feel able to tell us as therapists when they find a boundary challenging. Even if they do, there may not be much room for negotiation, for example because of service pressures. When clients find this challenging and distressing, the therapist may be faced with the dilemma of maintaining the boundaries or adapting in some way to the client. As in my case with my research, supervision is likely to provide an important space for the therapist to think this through.

Another part of my frustration in dealing with the research committee was that I did not understand their position, and therefore I thought they were being pedantic. I had proposed a randomised trial, but the committee highlighted that for randomisation to be adequate, it must involve concealed allocation. This is where the researcher does not know the treatment condition to which the next participant will be allocated (Gluud, 2006). This was not part of my proposal, so I tried to adapt it and suggested that I use sealed envelopes, so that I could not see which treatment condition was next. The committee did not agree to this, highlighting concern about the researcher being involved with the randomisation process. Instead, they proposed that a supervisor generated the randomisation sequence, and that I contact her each time a participant was recruited, to be advised of the treatment condition.

I initially felt that their proposal was impractical, which increased my sense of frustration. I intended to recruit 70 participants and the idea of

contacting my supervisor so many times felt unreasonable, particularly given that I needed a response quite quickly. In supervision, though, I was encouraged to use my formulation skills to think about the situation from the committee's perspective. Psychological formulation is a core competency of a Clinical Psychologist (British Psychological Society, 2006), and these skills helped me to find ways of understanding the committee's perspective and integrating this with mine.

Thinking about the committee's reasons helped me to better understand why they would not negotiate. Research needs to be as reliable as possible in order to be clinically useful, and the purpose of concealed allocation is to avoid bias. For example, if the next allocation is known, the researcher could manipulate recruitment of certain participants in order to produce results that favour the perceived superior treatment (Klein et al., 1995). Even though I did not believe that I would manipulate the study, I could acknowledge the benefit of minimising biases as much as possible, because I wanted my research to be meaningful. Thus, even though it felt at the time as though the research committee were being pedantic, I came to accept that they were trying to ensure good quality research is conducted. This helped to reduce my frustration. It also enabled me to be adaptable, because I changed my research proposal to incorporate their approach. This experience highlights the importance of supervision in research, not just in clinical work, as it protects against emotional exhaustion (Knudsen, Ducharme, & Roman, 2008) and positively impacts on therapist self-awareness and self-efficacy (Wheeler & Richards, 2007).

It is not always easy negotiating the choice between adapting something external and being adaptable yourself, and this choice might present itself in carrying out the duties of a qualified Clinical Psychologist. This is a multifaceted role, involving service delivery as well as psychological intervention with clients (British Psychological Society, 2006), and there may be different and conflicting pressures on these aspects of the role. It is likely a great skill to decide when an existing structure needs adapting, as part of our service delivery role, and when we need to be adaptable to fit with these structures, as part of our clinician role. In addition to engaging in supervision and using formulation skills, reflective practice and both critical and evaluative thinking are two further skills of a Clinical Psychologist that may be helpful in making and coping with such decisions (British Psychological Society, 2006).

Process of Adaptation

There is an idea in Personal Construct Psychology that I think nicely reflects the process of adaptation: that of loose versus tight construing. We can create something new by successively loosening the ways that we construe or interpret the world and then tightening up to a clear outcome; this is described as the Creativity Cycle (Walker & Winter, 2007).

Thinking in this way, I was tight about how I wanted to conduct my research. This meant I was resistant to the committee's suggestions for change, and resistance is a typical and unavoidable part of the change process (Wilkin, Bowers, & Monk, 1997). I subsequently loosened my ideas

about my research and acknowledged the value of the committee's suggestions, so tightened up with a new research proposal. Supervision was crucial in supporting that process. Through supervision, I was able to think about the research situation from a different perspective, and when my perspective changed, my response to the research committee changed.

There are parallels between this and our client work; clients may benefit from loosening their interpretations on a particular focus and tightening on a slightly different focus. There are also parallels with the service delivery aspect of our Clinical Psychologist role; a service may be tight on the focus of its work and staff may display resistance to adapting to a looser structure, or it may be that a service could be performing more effectively with a tighter focus. Through clinical training and practice, we are well equipped with a multitude of complex skills to support these processes.

The process of change can be slow, as I found in my encounter with the research committee, and as is often the case in client work. I have also observed how long it is taking for the process of change to happen in relation to working effectively with older adults, having reviewed the literature on cognitive-behavioural therapy with older people in the first chapter of this thesis. I concluded that this may be due to a focus on adapting the therapy, instead of on being adaptable to the individual. In Personal Construct Psychology terms, this could be described as being too tight on one question, and the solution may lie in loosening our thinking to include other ways of making therapy effective for older adults.

Conclusion

Some boundaries and structures are helpful, or can be adapted to make them more helpful. When they are not amenable to change, however, it can feel challenging. It is understandable to feel resistant, and it can feel easier to place the responsibility for change within the structure itself rather than within ourselves, but supervision can support the process of change within the individual, as therapy can for the client. This enables the individual to be more adaptable; for example, the next time I encounter a challenging structure, I may be less likely to feel resistant and more likely to reflect on and formulate the situation to see what can be changed. Clinical training has developed a wide range of skills and competencies, which will be valuable in making adaptations and being adaptable as a qualified Clinical Psychologist.

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Appendix A: Ethical Approval from Coventry University

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Diane Greenwood.....

Faculty/School/Department: [Faculty of Health and Life Sciences] Psychology

Research project title: A qualitative exploration of volunteers' experiences of befriending people with dementia

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

In general the proposal is ethically sound. It appears to lack a process for offering participants a summary of the results of the study and would benefit from inclusion of this. In addition, the proposed study appears "light" on credibility/validity checks which form a core part of qualitative methodologies. It is strongly recommended that the applicant should include additional procedures in this regard, such as independent coding of section of transcript with another researcher(s) or other similar credibility/validity checks.

The study relies on recruitment from just one site. The applicant is advised to check that sufficient participants will be available at this site and, if not, to consider other options for recruitment. Also, gatekeeper permission (written permission to conduct the study at this site) should be obtained.

2. Evaluation of the participant information sheet and consent form:

The Patient Information Sheet is generally ethically appropriate, though should include reference to how participants may obtain summary results of the study.

The Consent form is also ethically appropriate.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

| | |
|-------------------------------------|---|
| <input type="checkbox"/> | Approved - no conditions attached |
| <input checked="" type="checkbox"/> | Approved with minor conditions (no need to re-submit) |
| <input type="checkbox"/> | Conditional upon the following – please use additional sheets if necessary (please re-submit application) |
| <input type="checkbox"/> | Rejected for the following reason(s) – please use other side if necessary |
| <input type="checkbox"/> | Not required |

Name of reviewer: Anonymous.....

Date: 28/11/2013.....

Appendix B: Journal Submission Guidelines

- Clinical Psychology Review
- Dementia
- Reflective Practice

Clinical Psychology Review

DESCRIPTION

Clinical Psychology Review publishes substantive reviews of topics germane to clinical psychology. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology. Reviews on other topics, such as psychophysiology, learning therapy, experimental psychopathology, and social psychology often appear if they have a clear relationship to research or practice in clinical psychology. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies and theoretical treatises or clinical guides without an empirical base are not appropriate.

PREPARATION

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop <http://webshop.elsevier.com/languageediting/> or visit our customer support site <http://support.elsevier.com> for more information.

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: <http://www.elsevier.com/guidepublication>). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered. Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text. It is authors' responsibility to ensure their reviews

are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines for guidance in preparing manuscripts (<http://www.prisma-statement.org/statement.htm>). Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Appendices

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

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and the e-mail address of each author within the cover letter.

Corresponding author. Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail and postal address.

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the research purpose, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Graphical abstract

A Graphical abstract is optional and should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership online. Authors must provide images that clearly represent the work described in the article. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Minimum of 531 × 1328 pixels (h × w) or proportionally more. Preferred file types: TIFF, EPS, PDF or MS Office.

Highlights

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

Keywords

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

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many word processors build footnotes into the text; this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Table footnotes

Indicate each footnote in a table with a superscript lowercase letter.

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- Embed the used fonts if the application provides that option.
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EPS (or PDF): Vector drawings, embed all used fonts.

TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

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- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

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Tables

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found

at <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

Citation in text

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

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue

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This journal has standard templates in key reference management packages EndNote (<http://www.endnote.com/support/enstyles.asp>) and Reference Manager (<http://refman.com/support/rmstyles.asp>). Using plug-ins to wordprocessing packages, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style which is described below.

Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).

Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59.

Reference to a book: Strunk, W., Jr., & White, E. B. (1979). *The elements of style*. (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

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One author has been designated as the corresponding author with contact details:

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- Phone numbers

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Further considerations

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Dementia

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Appendix C: Literature Review Papers

- Literature Search Strategy
- Summary of Included Papers and Findings
- CBT Modifications Made for Older People

Literature Search Strategy

| Database searched | Key words | Search area | Limiters | No. of papers found |
|--|---|---|--|---------------------|
| Academic Search Complete; PsycINFO; MEDline | ("CBT" OR "cognitive-behav* therapy") AND ("anx*" OR "depress*") NOT ("Parkinson" OR "dement*" OR "alcohol" OR "bi-polar" OR "pain" OR "diabetes" OR "cancer") | "Subject terms" ("Title" for 'NOT' terms) | Include peer-reviewed journals, English-language articles, 'older adult' age-group (65+ years). Exclude dissertations. | 245 |
| | ("phobia" OR "trauma" OR "PTSD" OR "OCD" OR "obsessive compulsive" OR "hoarding" OR "GAD" OR "generalised" OR "panic" OR "acute stress disorder" OR "social anxiety") AND ("older" OR "elderly" OR "geriatric" OR "late life" OR "aging" OR "aged") AND ("CBT" OR "cognitive-behav* therapy") | "Subject terms" | Include peer-reviewed journals, English-language articles, 'older adult' age-group (65+ years). Exclude dissertations. | |
| ScienceDirect | ("CBT" OR "cognitive-behav* therapy") AND ("anx*" OR "depress*") | "Key words" | Include articles in press, Psychology-related articles, 'article' documents | 170 |
| Zetoc | "cognitive-behav* therapy" AND "anx*" | "Title" | N/A | 72 |
| | "cognitive-behav* therapy" AND "depress*" AND "older" | "Title" | N/A | |
| Cochrane Library | "cognitive-behaviour therapy" AND "anxiety" AND ("older adults" OR "elderly" OR "late-life") | "Title, Abstract, Key words" | N/A | 110 |
| | "cognitive-behaviour therapy" AND "depression" AND ("older adults" OR "elderly" OR "late-life") | "Title, Abstract, Key words" | N/A | |
| PsycINFO ('Related records' and 'Citations') | N/A | N/A | N/A | 14 |
| | | | | 611 |

Summary of Included Papers and Findings

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|------------------------|---|--|---------------------|---|--|
| Areán et al. (2005) | 67 with major depressive disorder or dysthymia 65.3 years (not reported) | Cognitive- behavioural group therapy (CBGT) Clinical case management (CCM) CBGT plus CCM (CBGT+) | HAM-D SF-36 | Pre- to post- treatment (6 months) 6-month follow-up 12-month follow-up | At 12-month follow-up, CCM and CBGT+ clients showed improvements in depressive symptoms but not in functioning, whereas CBGT clients showed improvements in functioning but not in depressive symptoms. The authors concluded that disadvantaged older adults with depression benefit from increased access to social services, either alone or combined with psychotherapy. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--------------------------|--|--|--|--|--|
| Laidlaw et al. (2008) | 40 with depression CBT 74.00 years (not reported) TAU 74.05 years (not reported) | Individual cognitive- behavioural therapy (CBT) Treatment as usual (TAU) | BDI-II BHS GDS HAM-D PSWQ SADS-L WHOQOL-Bref | Pre- to post- treatment (18 weeks) 3-month follow-up 6-month follow-up | Participants in both groups showed improvement at post-treatment and 6-month follow-up. Adjusted analyses indicated that CBT participants achieved significantly better outcomes than TAU participants on measures of hopelessness and depression at 6-month follow-up. Significantly fewer CBT participants met criteria for depression diagnosis than TAU participants at 3-month follow-up. The authors concluded that CBT for depression can be beneficial in a primary care population, and particularly impacts on levels of hopelessness. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|-------------------|---|--|---|---|---|
| Mohlman (2008) | 8 with Generalised Anxiety Disorder (GAD) 66.4 years (60-74) | Group CBT CBT plus Attention Process Training (CBT/APT) | Self-report: BAI BDI PSWQ STAI (Trait subscale) Neuropsych.: AITB BNT COWAT Stroop CW WAIS-III | Pre- to post- treatment (8 weeks) 6-month follow-up | CBT/APT participants significantly outperformed CBT participants in executive skills. At follow-up, more CBT/APT than CBT participants met criteria for high end-state functioning, and twice as many achieved the criteria for response in CBT/APT (100%) than CBT (50%). Also, the linear trend of the PSWQ, but not the Stroop, was significantly steeper for CBT/APT clients than CBT clients. The author recommended continued investigation into the role of executive skills in CBT outcome and anxiety treatment. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--|--|--|--|--|--|
| Mohlman, Kleber & Gorman (2003) | Study 1: 27 with GAD, 66.4 years (60-74) Study 2: 15 with GAD, 67.5 years (60-79) | Study 1: Individual CBT Wait-list (WL) Study 2: Enhanced individual CBT (ECBT) Wait-list (WL) | BAI BDI PSWQ SCID SCL-90-R STAI (Trait subscale) | Pre- to post- treatment (13 weeks) 6-month follow-up | Study 1: The CBT group significantly improved on GAD severity but WL did not. Study 2: Compared with WL, ECBT patients significantly improved on two self-report measures, GAD rates and severity. Overall: Effect sizes were slightly larger in ECBT than in CBT. There was increased homework compliance in Study 2 than in Study 1. Authors recommended enhancing standard CBT protocols for late-life GAD. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--------------------------------------|---|---|---|--|---|
| Schuurmans et al. (2006, 2009) | 84 with GAD, panic disorder with/out agoraphobia, agoraphobia without panic disorder, or social phobia Total 69.80 CBT 70.71 SL 69.79 WL 66.85 (Not reported) | Individual CBT Sertraline (SL) Wait-list (WL) | 2006 paper: Primary: BAI HAM-A Secondary: CES-D WDQ (Dutch adaptation) 2009 paper: BAI CES-D HAM-A WDQ | 2006 paper: Pre- to post- treatment (13 weeks) 3-month follow-up 2009 paper: 1-year follow-up | At post-treatment, CBT and SL participants improved significantly on every measure. At 3-month follow-up, SL participants showed greater improvement on worry symptoms. At follow-up, effect sizes for CBT were small to medium, but large for SL. There were no significant group differences in treatment response or high end-state functioning. More research on pharmacological treatment of late-life anxiety and adaptations for CBT with older adults was suggested. At 1-year follow-up, there were no significant differences in the relative effectiveness of CBT and SL, though the SL group showed more improvement on worry and anxiety. Effect sizes were small to moderate for CBT but moderate to large for SL. The authors concluded that the long-term use of sertraline might be more beneficial for late-life anxiety than standard individual CBT, and that more research is needed to adapt CBT for anxiety successfully to older adults. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--|---|---|---|---|---|
| Serfaty, Haworth & Buszewicz (2009) | 204 with depression Total 74.1 years TAU 72.8 years TC+ 75.0 years CBT+ 74.4 years (Not reported) | TAU TAU plus talking control (TC+) TAU plus individual CBT (CBT+) | Primary: BDI-II Secondary: BAI Euroqol SFQ | Pre- to post- treatment (up to 12 sessions) 4-month follow-up 10-month follow-up | Reductions in depression scores were more significant for CBT+ than for TC+ or TAU. A significant improvement on the depression measure was found per therapy session for CBT+ but not for TC+ or TAU. The authors concluded that individual CBT is an effective treatment for older people with depressive disorder. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|------------------------------------|--|--|---|---|--|
| Stanley, Beck, et al. (2003) | 85 with GAD 66.2 years (not reported) | Group CBT Minimal contact (MC) | Primary: HAM-A PSWQ STAI (Trait subscale) WS Secondary: BDI FQ (revised) GDS (15- item version) HAM-D LSI-Z QOLI | Pre- to post- treatment (15 weeks) 3-month follow-up 6-month follow-up 12-month follow-up | At post-treatment and 12-month follow-up, there was greater improvement for CBT than MC participants on measures of worry, anxiety and depression. At post-treatment, CBT participants showed a greater response rate (45%) compared with MC clients (8%), and fewer met criteria for GAD (55% in CBT compared with 81% in MC). Post-treatment scores for CBT participants did not show a return to normative functioning, though. The authors concluded there is strong support for the potential use of CBT for late-life GAD. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--|---|--|-------------------------------------|---|--|
| Stanley, Hopko, et al. (2003) | 12 with GAD 70.6 years (62-79) | Individual CBT for older adults with GAD in primary care (PCBT) Usual care (UC) | BAI BDI PSWQ QOLI SF-36 | Pre- to post- treatment (approx. 8 weeks) | Results suggested significant reductions in GAD severity, worry and depression for PCBT but not for UC participants. All five PCBT participants met response criteria, compared with one UC client. The authors concluded adding PCBT to usual care appeared to have been beneficial. |
| Thompson, Coon, Gallagher- Thompson, Sommer & Koin (2001) | 100 with depression Total 66.8 years (not reported) CBT 66.5 years DP 66.8 years CBT+DP 67.2 years | Individual CBT Desipramine (DP) CBT plus DP (CBT+DP) | BDI (short form) HAM-D | Pre- to post- treatment (approx. 3-4 months) | The CBT+DP group showed greater improvement than the DP group. There was little difference between CBT and CBT+DP groups. CBT participants improved more than DP participants on self-report measures of depression. The authors concluded CBT deserves greater attention in late-life depression treatment. |

| Study | Participants: Number, symptoms, mean age (range) | Treatment groups | Outcome measures | Assessment (duration) | Main findings |
|--|--|---|--|--|---|
| Wetherell, Gatz & Craske (2003) | 75 with GAD 67.1 years (not reported) | Group CBT Discussion group (DG) Wait-list (WL) | ADIS-IV BAI BDI HAM-A HAM-D MOS-SR-SF PSWQ | Pre- to post- treatment (12 weeks) 6-month follow-up | Participants in both active conditions improved relative to WL. At post-treatment, there was better improvement for CBT than DG participants on one worry measure. At 6-month follow-up, gains were maintained for both groups, but there were no differential treatment effects. Effect sizes were large for CBT, small to medium for DG and virtually none for WL. The authors concluded that brief treatment of late-life GAD is beneficial, but that there is limited support for the superiority of CBT to a credible comparison intervention. |

Note. ADIS-IV = Anxiety Disorders Interview Schedule; AITB = Army Individual Test Battery; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; BHS = Beck Hopelessness Scale; BNT = Boston Naming Task; CES-D = Centre for Epidemiological Studies Depression Scale; COWAT = Controlled Oral Word Association Test; FQ = Fear Questionnaire; GDS = Geriatric Depression Scale; HAM-A = Hamilton Rating Scale for Anxiety; HAM-D = Hamilton Depression Scale; LSI-Z = Life Satisfaction Index-Z; MOS-SR-SF = Medical Outcomes Study self-report health survey, short form; Neuropsych. = neuropsychological tests; PSWQ = Penn State Worry Questionnaire; QOLI = Quality of Life Inventory; SADS-L = Schedule for Affective Disorders and Schizophrenia, Life time version; SCID = Structured Clinical Interview for DSM-IV Disorders; SCL-90-R = Symptom Checklist-90-Revised; SFQ = Social Functioning Questionnaire; SF-36 = Short-Form Health Survey; STAI = State-Trait Anxiety Inventory; Stroop CW = Stroop Colour-Word Interference Trial; WAIS = Wechsler Adult Intelligence Scales; WDQ = Worry Domain Questionnaire; WHOQOL-Bref = World Health Organisation Quality of Life scale, short form; WS = Worry Scale.

CBT Modifications Made for Older People

| Study | Modifications |
|-----------------------|---|
| Areán et al. (2005) | “Treatment was modified specifically for low-income, low-education older adults, under the guidance of Gallagher-Thompson, Thompson and Miranda” |
| Laidlaw et al. (2008) | “CBT...was administered according to specific modifications for use with older adults in procedures described in a comprehensive treatment manual specifically developed for the study” |
| Mohlman (2008) | <ul style="list-style-type: none"> • “A slow pace was used, with frequent repetition of concepts” • “All clients received the ‘Mastery of Your Anxiety and Worry’ client workbook” • “Homework was assigned in each session, and one example of each assignment was completed before the client left the session so that the therapist could ensure that the participant understood the assignment” • “Midweek homework troubleshooting phone calls were made by the therapist for the first four assignments” • “All homework assignments were photocopied and returned with ample feedback for correcting mistakes and improving CBT skills” |

| Study | Modifications |
|-----------------------|--|
| Mohlman et al. (2003) | <p>“Enhanced CBT included the same therapists’ manual and modules as in Standard CBT, with the addition of learning and memory aids designed to a) increase homework compliance, b) strengthen memory for techniques, and c) facilitate the use of these techniques. These consisted of:</p> <ul style="list-style-type: none"> • Weekly reading assignments in the ‘Mastery of Your Anxiety and Worry’ client workbook (meant to reinforce session material) • Graphing exercises in which patients charted numerical mood ratings averaged over each week (meant to highlight gradual progress, reveal patterns in moods, and facilitate discussion) • Mid-week homework reminder / troubleshooting phone calls from the therapist for the first four assignments (meant to alleviate patients’ ambivalence about asking for help and review the procedures and goals of the assignment) • Inclusion of a homework-compliance requirement of no more than three missed assignments (meant to emphasise the importance of consistent, independent work) <p>All participants were also asked to use a perspective-taking strategy to facilitate evidence generation in cognitive restructuring exercises. First, each participant generated a list of three to five individuals who they believed were good problem-solvers. Then, evidence that refuted automatic thoughts was generated from the perspective of each person on the list. This technique was meant to reduce automatic negative thoughts through the enhancement of generative thinking abilities and broadened perspectives.</p> <p>Also, all homework assignments were photocopied and returned with ample feedback for correcting mistakes and improving CBT skills.</p> <p style="text-align: right;">Contd. on next page</p> |

| Study | Modifications |
|-----------------------------------|--|
| Mohlman et al. (2003) | <p>“During the last five minutes of each session, the therapist led an ‘expanding review’ of all concepts (e.g. the three-systems model of emotion) and techniques (e.g. progressive muscle relaxation) learned to date, with a brief summary of when techniques should be used (e.g. ‘whenever you have a catastrophic or worrisome thought, write it down, then weigh the evidence and turn it into a less negative thought’). At the mid-point of treatment, responsibility for leading expanding review was transferred to the client. This technique was intended to strengthen memory for, and facilitate use of, CBT concepts and skills.</p> <p>The enhancements were derived from articles and workshop material focused on tailoring CBT to older adults or were devised by the first author.”</p> |
| Schuurmans et al. (2006, 2009) | <p>“Treatment protocols for CBT... were adapted for use with older adults; our CBT protocol consisted of:</p> <ul style="list-style-type: none"> • 15 sessions • Allowing more attention to psychoeducation • Repeated explanation and revision of new information and newly-learned coping skills” |

| Study | Modifications |
|------------------------------|--|
| Serfaty et al. (2009) | <ul style="list-style-type: none"> • “CBT techniques were modified for use in older people, with increased structure of the sessions and techniques to facilitate recall. • Where relevant, specific issues associated with old age were addressed with exploration of patients’ beliefs about the negative effects of physical ill health and their perceptions of themselves in the context of their age. • ‘The Feeling Good Handbook’, originally developed for use with older people, was given to all participants as an adjunct to therapy, with selected chapters recommended for reading. • The National Institute of Clinical Excellence guidelines recommend that six to eight sessions of CBT be given to depressed adults in a primary care setting. Up to 12 sessions were offered because older people may take longer to learn CBT techniques. • For those unable to travel, home visits were offered.” |
| Stanley, Beck, et al. (2003) | <ul style="list-style-type: none"> • “CBT was... adapted and standardised for use with the elderly in an earlier treatment study” |

| Study | Modifications |
|-------------------------------|--|
| Stanley, Hopko, et al. (2003) | <p>“PCBT was developed on the basis of cognitive-behavioural procedures with demonstrated efficacy in academic clinical trials of late-life GAD, with modifications to meet the needs of older medical patients. Initially, a six-session PCBT manual was developed and administered in an open trial to eight medical patients with GAD. Data from this open trial suggested the potential usefulness of PCBT. However, we subsequently refined the manual to enhance outcome and address qualitative feedback from therapists and patients about usability of treatment.</p> <ul style="list-style-type: none"> • The duration of treatment was increased from six to eight sessions, with two additional sessions allowed for patients experiencing immediate crises or needing additional time to learn coping skills • Many treatment procedures (e.g. mnemonic aids, terminology used) and homework forms also were simplified • Flexibility was recommended in the use of terminology, mode of presentation, and homework format to fit individual differences in educational backgrounds, cognitive skills, and sensory capacity • Therapists were encouraged to be flexible with the schedule of sessions to accommodate individual patient needs |
| Thompson et al. (2001) | <p>“... specific modifications for older individuals... involved:</p> <ul style="list-style-type: none"> • Strategies to facilitate learning, such as repeated presentation of information using different modalities, slower rates of presentation, greater use of practice and so forth • Greater use of structure and modelling behaviour” |

| Study | Modifications |
|-------------------------|--|
| Wetherell et al. (2003) | <ul style="list-style-type: none"> ▪ “The overall program was advertised as ‘worry reduction classes’ because research has suggested that older adults may resist services labelled as mental health treatment” ▪ They “met 90 minutes weekly in one of five community locations most convenient to participants” <p>“Leaders used a manual... with minor modifications for older adults:</p> <ul style="list-style-type: none"> ▪ Elements such as time management and benzodiazepine withdrawal were omitted ▪ Examples were made more relevant to older people” |

Appendix D: Dementia Befriending Services Information

The Service

The services began in 2009 and are partly funded by the local NHS Trust. Clients are older people with mild / early stage dementia who have little or no contact with other services or sources of support. Befrienders visit clients on a one-to-one basis for 1-3 hours a week. They provide:

- a) Company and activity.
- b) Support to maintain hobbies, interests and skills.
- c) Assistance to access the local community.
- d) Signposting of any issues and concerns to the appropriate services.

In each of the two locations, the service supports around 40-50 clients and has around 30 befrienders. Clients can refer themselves, or can be referred by other local organisations such as the Alzheimer's Society, the Community Mental Health Team and the Social Services team.

Befrienders

The role is advertised in the local newspaper and on the Age UK Camden / Age UK Coventry website. There is a specific recruitment drive approximately twice a year. Befrienders vary in age, gender and background. It is important that they have qualities including good communication skills, empathy with the needs of older people, and patience and sensitivity. All befrienders undergo a Criminal Records Bureau check.

Training

Each new befriender attends two half-day training sessions: a general induction to Age UK Camden / Age UK Coventry services and a dementia awareness session. Befrienders also have access to local training opportunities.

Getting Started

Each client is assessed by the Service Coordinator before being matched to a befriender. Befriending matches are based on numerous factors including personality and common interests. The Coordinator personally introduces each befriender to their potential match, and both the client and befriender can accept or decline the match. Regular visits are then arranged between the client and befriender.

Befriender Support

This is provided in a range of ways, including individual face-to-face contact, email and telephone support. Befrienders provide monthly written feedback, which helps the Coordinator to identify any specific support needs for the client or befriender. In addition, there is a monthly befriender newsletter. Furthermore, quarterly group support sessions and other social events give befrienders the opportunity to exchange ideas, experiences and information.

Sources of Information

Age UK Camden. (2011). *Dementia befriending service*. Retrieved from <http://www.ageuk.org.uk/camden/our-services/dementia-befriending-service/>

Age UK Coventry. (2011). *Volunteer Information Pack*.

Cressey, M. (2012). Volunteer befrienders: Can it work? *Journal of Dementia Care*, 20(5), 15-16.

N. Lavin, personal communication, December 6, 2013.

T. McDermott, personal communication, December 16, 2013.

Appendix E: Participant Documentation

- Information Sheets (Locations A and B)
- Consent Form
- Demographic Questionnaire

Information Sheet (Location A)

Coventry University
Priory Street, Coventry CV1 5PB
Telephone 024 7665 5325
Fax 024 7665 5702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



PARTICIPANT INFORMATION SHEET

Study title: A qualitative exploration of volunteers' experiences of befriending people with dementia.

My name is Diane Greenwood and I am the Chief Investigator for this research study, which forms part of my Doctorate in Clinical Psychology. Please read the following information, if you would like to take part in the study, which runs from December to February, or if you have any questions, please contact me (details at end). Participation is entirely voluntary.

What is the study about?

The aim of the study is to learn about the experiences of people who volunteer as befrienders to people with dementia. There is some research on the experiences of a) paid dementia workers and b) community or hospice volunteers, but there is very little research on dementia volunteers. Volunteers are an important part of the care that enables people with dementia to stay in their own homes, so it's important to better understand their experiences. It is hoped that this research may give other workers a better understanding of what it is like to support people with dementia, and may inform the support that volunteer befrienders receive in the future. It may also help to find ways of recruiting more volunteer befrienders.

Why have I been invited to participate?

All volunteers who have been working for Age UK Camden's Dementia Befriending Service and who have made a minimum of two visits have been invited to participate.

What would I have to do if I took part?

I will arrange to meet with you at a place and time that is convenient for you, to conduct an interview with you. This will last approximately one hour, depending on how much you wish you share with me, and it will be digitally recorded.

When we meet, I will discuss the study with you and answer any questions you have. I will then ask you to sign a consent form and complete a brief questionnaire (e.g. age, ethnicity). I will then carry out an interview with you, which will involve asking about your experiences of being a volunteer befriender to people with dementia. Afterwards, you will have the opportunity to reflect on the interview and raise any queries.

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Head of Department of Psychology
Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

What are the potential drawbacks and benefits to taking part?

In terms of drawbacks, you will be asked to give up your time to complete the interview. Also, as with most research, it is possible that participation may raise difficult or emotive issues. It is up to you how much information you share in the interview, but the interview can be stopped at any time, and immediate support and information can be given, e.g.:

- *APT*, an information, advice and therapy service: 0845 521 6100
- *Camden Listening and Counselling Centre*, a charity offering a listening service and a counselling service: 020 7482 6200 or camdenlistening@yahoo.co.uk
- *Samaritans*, a charity offering 24-hour confidential emotional support: 08457 909 090
- *Alzheimer's Society*, a charity supporting people with dementia, their families and carers: 0207 581 4828 or marie.sawyer@alzheimers.org.uk

In terms of benefits to taking part, you will add to our knowledge of the experience of volunteers who support people with dementia. We hope this will help other dementia workers and volunteers to understand what it is like to work with dementia, and it may help us to better support volunteer befrienders in the future. It may also help us to find ways of recruiting more volunteer befrienders.

What will happen to my interview?

Once completed, your interview recording will be transcribed verbatim and any personal identifiable information will immediately be deleted from the transcript. After this, the transcript will be analysed with other participants' interviews.

The results will be written up as part of a doctoral thesis. This may include direct quotes from your interview, but these will be anonymous and you will not be identified in the report. It is also hoped that the results will be published in a peer-reviewed journal. You are very welcome to have a summary copy of the results; the consent form gives you the opportunity to say whether or not you would like this.

Will my information be confidential?

All information you provide will be kept confidential and will be used for the sole purpose of the current study. As soon as your interview is transcribed, it will be made anonymous using a pseudonym. Only I will know the names and contact details of participants, and this confidentiality will only be broken if researchers have concerns about your or others' safety. In these circumstances, the researchers will always try to discuss their concerns with you before breaking confidentiality.

I will only share your information after it has been anonymised, at which point it is likely to be shared with the other researchers in the team (named on this information sheet). Relevant sections of anonymous data may also be looked at by a) members of a peer supervision group, to ensure reliability of analysis; and b) individuals from Coventry University or regulatory authorities, to ensure the study is being carried out correctly.

How will my data be stored?

Electronic data will be stored as a password-protected computer file, and audio-taped and transcribed information will be stored securely in a locked cabinet.

Interview recordings will be deleted as soon as they are transcribed, and your name and contact details will be deleted as soon as the research is completed. Anonymous data will be stored securely at Coventry University for five years, after which it will be deleted.

What if I change my mind about taking part?

You can withdraw your data at any time before it is analysed in March 2014, without giving a reason. You can do this by contacting me (details below).

Who reviews and supervises the research?

The research has been approved by Coventry University Ethics Committee. It is directly supervised by three Clinical Psychologists, and is overseen by two tutors on the Clinical Psychology Doctorate at Coventry University.

Thank you for your time. To participate, or for further information, please contact:

| | | |
|---|--|---------------|
| Diane Greenwood (Chief Investigator) | greenwo8@uni.coventry.ac.uk | 02476 887 806 |
| Dr Carolyn Gordon (Research Supervisor) | ab0477@coventry.ac.uk | 02476 887 808 |
| Dr Jessica Bolton (Research Supervisor) | ab0710@coventry.ac.uk | 02476 888 328 |
| Dr Claire Pavlou (Clinical Supervisor) | claire.pavlou@coventry.ac.uk | 02476 707 962 |

Information Sheet (Location B)

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7685 8328
Fax 024 7685 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eva Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



PARTICIPANT INFORMATION SHEET

Study title: A qualitative exploration of volunteers' experiences of befriending people with dementia.

My name is Diane Greenwood and I am the Chief Investigator for this research study, which forms part of my Doctorate in Clinical Psychology. Please read the following information. If you would like to take part in the study, which runs from December to February, or if you have any questions, please contact me (details at end). Participation is entirely voluntary.

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The aim of the study is to learn about the experiences of people who volunteer as befrienders to people with dementia. There is some research on the experiences of a) paid dementia workers and b) community or hospice volunteers, but there is very little research on dementia volunteers. Volunteers are an important part of the care that enables people with dementia to stay in their own homes, so it's important to better understand their experiences. It is hoped that this research may give other workers a better understanding of what it is like to support people with dementia, and may inform the support that volunteer befrienders receive in the future. It may also help to find ways of recruiting more volunteer befrienders.

Why have I been invited to participate?

All volunteers who have been working for Age UK Coventry's Dementia Befriending Service and who have made a minimum of two visits have been invited to participate.

What would I have to do if I took part?

I will arrange to meet with you at a place and time that is convenient for you, to conduct an interview with you. This will last approximately one hour, depending on how much you wish you share with me, and it will be digitally recorded.

When we meet, I will discuss the study with you and answer any questions you have. I will then ask you to sign a consent form and complete a brief questionnaire (e.g. age, ethnicity). I will then carry out an interview with you, which will involve asking about your experiences of being a volunteer befriender to people with dementia. Afterwards, you will have the opportunity to reflect on the interview and raise any queries.

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Chair of Department of Psychology
Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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What are the potential drawbacks and benefits to taking part?

In terms of drawbacks, you will be asked to give up your time to complete the interview. Also, as with most research, it is possible that participation may raise difficult or emotive issues. It is up to you how much information you share in the interview, but the interview can be stopped at any time, and immediate support and information can be given, e.g.:

- *IAPT*, an information, advice and therapy service: 0845 521 6100
- *Light House*, a charity offering professional counselling: 024 7644 0095
- *Samaritans*, a charity offering 24-hour confidential emotional support: 08457 909 090
- *Alzheimer's Society*, a charity supporting people with dementia, their families and carers: 02476 652 602 or coventry@alzheimers.org.uk

In terms of benefits to taking part, you will add to our knowledge of the experience of volunteers who support people with dementia. We hope this will help other dementia workers and volunteers to understand what it is like to work with dementia, and it may help us to better support volunteer befrienders in the future. It may also help us to find ways of recruiting more volunteer befrienders.

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Once completed, your interview recording will be transcribed verbatim and any personal identifiable information will immediately be deleted from the transcript. After this, the transcript will be analysed with other participants' interviews.

The results will be written up as part of a doctoral thesis. This may include direct quotes from your interview, but these will be anonymous and you will not be identified in the report. It is also hoped that the results will be published in a peer-reviewed journal. You are very welcome to have a summary copy of the results; the consent form gives you the opportunity to say whether or not you would like this.

Will my information be confidential?

All information you provide will be kept confidential and will be used for the sole purpose of the current study. As soon as your interview is transcribed, it will be made anonymous using a pseudonym. Only I will know the names and contact details of participants, and this confidentiality will only be broken if researchers have concerns about your or others' safety. In these circumstances, the researchers will always try to discuss their concerns with you before breaking confidentiality.

I will only share your information after it has been anonymised, at which point it is likely to be shared with the other researchers in the team (named on this information sheet). Relevant sections of anonymous data may also be looked at by a) members of a peer supervision group, to ensure reliability of analysis; and b) individuals from Coventry University or regulatory authorities, to ensure the study is being carried out correctly.

How will my data be stored?

Electronic data will be stored as a password-protected computer file, and audio-taped and transcribed information will be stored securely in a locked cabinet.

Interview recordings will be deleted as soon as they are transcribed, and your name and contact details will be deleted as soon as the research is completed. Anonymous data will be stored securely at Coventry University for five years, after which it will be deleted.

What if I change my mind about taking part?

You can withdraw your data at any time before it is analysed in March 2014, without giving a reason. You can do this by contacting me (details below).

Who reviews and supervises the research?

The research has been approved by Coventry University Ethics Committee. It is directly supervised by three Clinical Psychologists, and is overseen by two tutors on the Clinical Psychology Doctorate at Coventry University.

Thank you for your time. To participate, or for further information, please contact:

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| Diane Greenwood (Chief Investigator) | greenwo8@uni.coventry.ac.uk | 02476 887 806 |
| Dr Carolyn Gordon (Research Supervisor) | ab0477@coventry.ac.uk | 02476 887 808 |
| Dr Jessica Bolton (Research Supervisor) | ab0710@coventry.ac.uk | 02476 888 328 |
| Dr Claire Pavlou (Clinical Supervisor) | claire.pavlou@coventry.ac.uk | 02476 707 962 |

Consent Form

Coventry University
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Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.PsyD., CPsychol

THE UNIVERSITY OF
WARWICK



ID: _____

PARTICIPANT INTERVIEW CONSENT FORM

Study title: A qualitative exploration of volunteers' experiences of befriending people with dementia.

Please read the points below and initial each box to indicate that you understand and agree to each point. Please then sign and date at the bottom of the page.

☐ I have read and understood the Participant Information Sheet for the above study. I have had the opportunity to ask questions or raise issues with the research team, and have had these answered satisfactorily.

☐ I give permission for my interview to be digitally recorded, transcribed and used anonymously for the purposes of research.

☐ All information will be confidential and anonymous, and I will not be identifiable to anyone other than the chief investigator. The only exception is if researchers have concerns about my or others' safety.

☐ I give permission for the chief investigator to share my anonymised data with a) the wider research team as identified on the Participant Information Sheet, b) a peer supervision group for analysis purposes, and c) individuals from Coventry University and regulatory authorities.

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Head of Department of Psychology
Professor James Trevelan BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3008
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☐ My participation in this study is voluntary and I can withdraw my consent at any time without giving a reason until data analysis (March 2014).

☐ I agree to take part in the above study.

☐ I would / would not like to receive a summary of the results.

Participant name

Participant signature

Date

Diane Greenwood
Chief investigator

Chief investigator's signature

Date

Demographic Questionnaire

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Telephone 024 7688 6325
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Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



ID: _____

Demographic questionnaire

What is your gender? (Please circle)

Male

Female

What is your age?

What is your ethnicity?

What is your first language?

How long have you been befriending?

_____ weeks

_____ months

_____ years

How many people do you befriend?

How old is the person / people you befriend? _____

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Appendix F: Interview Schedule

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Programme Director
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Dr Eve Knight
BSc Clin.PsyD, CPsychol

THE UNIVERSITY OF
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Interview schedule

1. Informed consent

- Participant to read through information sheet and ask any questions.
- Participant to sign two consent forms (one for them; one for researcher).
- Participant to complete demographic questionnaire.

2. Disclaimer

This is not a therapy session, though sensitive issues may come up and the researcher can provide contact details for appropriate support, e.g.:

- IAPT (0845 521 6100).
- Light House (024 7644 0095).
- Samaritans (08457 90 90 90)
- Alzheimer's Society (02476 652 602 or coventry@alzheimers.org.uk).
- Also can go to GP or Age UK Volunteer Coordinator.

3. Interview set-up

- Approximate duration of interview and participant can end interview at any point. Can withdraw from the study up until the point of data analysis.
- There is no right or wrong answer.
- More of a 'one-sided chat' than an interview.
- May ask questions that seem silly or obvious but want to avoid assumptions.
- May take notes during interview.

4. Interview questions

- First of all, could you just tell me a bit about your role as a volunteer befriender to people with dementia?
- I'm interested in what makes the befriender role different from other roles.
- Ok, you've told me about your role from your point of view. What do you think the person you visit thinks your role is?
- So we've talked about what your role is. Now I'm wondering what it's like for you doing that role. Can you tell me about a visit that comes to mind?
- Ok so we've talked about what your role is and what it's like for you. The last thing I'd like to ask is what are your experiences of support for you in your role?

Prompts and probes:

- *Could you say a little more? / Could you give me more detail?*
- *What was that like for you?*
- *Was there another time that...? / Can you give me another example?*
- *What do you mean by 'X'?*
- *Are you ok to talk about that more? (if sensitive topic)*

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Head of Department of Psychology
Professor James Trevelan BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3006

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5. Debrief

- a. How did you find the interview?
- b. Was there anything that didn't come up that you were expecting to come up?
- c. Is there anything you'd like to add?
- d. Explain intentions of study and what will happen to data / results.
- e. Remind who to contact if they have questions or if they need further support.
- f. Thank you!

6. Reflexive diary time

E.g. What was I feeling and thinking throughout?
What do I feel now?
What themes piqued my interest?
What do I believe I brought to the interview?
How do I believe I may have influenced the data?

Appendix G: Reflexive Diary Extracts

Thursday 29th August 2013

I'm doing this research because I want to explore what it's like for the person – to be a volunteer, to work with people with dementia who are declining, to be able to help, or perhaps to feel frustrated. I imagine it would be more satisfying than stressful, because it would feel like you're making a difference and meeting people's needs – but the literature on dementia staff and other volunteers is commonly about stress and burnout. Perhaps because they're volunteers it might be hard to say no or to know where their role ends?

Sunday 22nd September 2013

I need to stop using words like "impact" and "why" in this research. I've realised I'm hypothesising quite a lot. I wonder if that's the impact of my clinical training, where I hypothesise about clients all the time. I wasn't aware that I did it so much!

Thursday 17th October 2013

I feel as though I'm looking for something negative, as though it's only 'good' research if it finds that volunteers are stressed and burned out. If it's emotionally difficult for them, there are possible implications around training and support, but what are the clinical implications if they're ok? I discussed this with my research team, and realised there are different implications from positive psychology like resilience. It seems sad that I was so problem-focused that I didn't think about people's strengths.

Tuesday 12th November 2013

I realise I've been making assumptions about volunteers' experiences being difficult. I have to try and keep my interview questions neutral; for example I changed the question 'what helps you cope in your role?', because I was assuming that they would need to cope. This really shows the influence of the existing research base, because I initially thought that the findings would be positive but I've been thinking about the study in terms of burnout and stress. I must be open to their experiences; that's the point of this research!

Friday 13th December 2013

My first interview. I found it really emotional and moving, and it went much deeper than I thought in terms of what it means to be human and alive. It also surprised me when he talked about being afraid of his befriender dying. I suppose I was imagining he would talk about him as an individual, not about them and their relationship. I guess that shows my assumptions about befriending being something individual rather than relational.

Wednesday 22nd January 2014

My fourth interview. I remember thinking we went quite deep quite quickly, and I wondered whether I should be holding back more. It's a different position as a researcher compared with being a clinician; it didn't feel quite as safe. I was conscious of trying not to say anything too leading, so I wasn't responding in the way I normally would as a clinician, which I found hard.

Wednesday 12th February 2014

My final interview. I was surprised that she would choose to support people with dementia after hearing her partner's stories about the people he supports. Perhaps that shows my assumptions about working with dementia; it shows how easy it can be to feel scared of it.

Wednesday 5th March 2014

Apparently I "light up" when I talk about my research. I feel like this reflects the magic I felt during the interviews. I'm worried that I'll lose this quality in the final paper if I use words like "reciprocal" instead of "loving relationships". My supervisor suggested writing about the way that befrienders spoke, to capture some of the 'feel' of the interviews while minimising my subjectivity.

Monday 14th April 2014

There are some quotes that fit the theme but feel too private to put out there in public, like how wearying and boring it can be. I feel like I'd be insulting them if I portrayed their experience as something emotionally draining, but perhaps I'm just worried about what other people will think of them. Maybe I've gone too much the other way in trying not to be problem-focused and ended up saying that befriending is mostly happy when they did say it's not always like that. I need to be ok with saying some uncomfortable things as part of presenting (my interpretation of) the whole experience, warts and all.

Friday 2nd May 2014

I can be too interpretative in my analysis. For example, I wrote that someone said something "beautifully". Better to say "she said it with warmth and passion". I've been immersed in my data throughout the analysis, but now I need to stand back from it so that I can capture the emotional side of things without placing value or judgement on them.

Saturday 17th May 2014

I 'promoted' Theme 2b ('Paradoxical Processes') from a subordinate to a superordinate theme. It seemed to be taking over and speaking for itself, and it was the essence of the original superordinate theme ('A Special But Complex Relationship'). The paradoxes are what made it special and complex, and 'paradoxical' is more objective than 'special', so it seems a more appropriate representation of the theme.

Appendix H: IPA Analysis

- Analysis Procedures
- Coded Transcript Extract
- Participant Example of Stages of Analysis
- Prevalence of Themes

Analysis Procedures

IPA Data Analysis Protocol (Smith, Flowers & Larkin, 2009)

1. Reading and re-reading: The researcher immerses themselves in the data by reading and re-reading the first transcript to ensure the participant becomes the focus of the analysis.
2. Initial noting: This stage is examination of semantic content and language use on a very exploratory level noting anything of interest within the transcript. This process encourages familiarity with the transcript and starts to identify ways in which the participant talks and thinks about an issue. The aim of this stage of analysis is to produce a comprehensive and detailed set of notes and comments on the data. Exploratory commenting is done with descriptive, linguistic and conceptual comments.
3. Developing emergent themes: Shifting to working primarily with the exploratory notes rather than the transcript itself to identify emergent themes. This is a more interpretative stance, a product of collaboration between both the researcher and participant. The task at this stage of analysis is to produce concise statements (themes) about what was important in the comments.
4. Searching for connections across emergent themes: This stage involves mapping how themes fit together. The outcome should be a structure which highlights the most interesting and important aspects of the participant's account.
5. Moving to the next case: The researcher moves to the next participant's transcripts and repeats steps 1-4 for each participant.
6. Looking for patterns across cases: This stage involves looking for patterns and connections across cases. This usually results in a table of themes for the sample and illustration for each theme for each participant.

Coded Transcript Extract

EMERGENT THEMES

feeling
lonely

interacting
with others

it doesn't
matter what
he has
dementia

can't talk
about nice
things

he can still
remember

relate to
each other

TRANSCRIPT (DAPHNE)

218 a functioning human being, because you're functioning with other people
219 [pause] as opposed to somebody who's just confused and stuck at home.

I: Being human as opposed to somebody with dementia?

222 D: Yes and he says to me, I'm not demented am I? And I say oh no
223 Norman we all forget things. So I mean, there's part of him that knows
224 he's demented, erm. but it's an ugly word isn't it, you know. and I say well
225 I can't remember everything, and actually in many cases he's got a much
226 better memory for who was in what film in the nineteen fifties than I have,
227 which is great and I say to him gosh you remember that well [pause] and
228 he remembers my family, and one or two people that I've introduced into
229 the conversation, and he nearly always asks after them, he says how's
230 your sister, has she met the Queen again [laughs] I say no no they're not
231 having tea this week, but of course then he goes straight back to his life,
232 and round and round and round. So his conversation about anybody that I
233 know or things I try to bring into the conversation lasts about, you know, a
234 couple of nanoseconds, and then we go back to what Norman's thinking
235 about, but he does remember, and he remembers extraordinary things
236 that I forget. I mean Tracey from Age Concern came up, and twice over a
237 period of a year she's come to the cinema with us, I know Norman likes
238 meeting people so I said to Tracey why don't you come to the movies with
239 us, and he was delighted he'd someone else to talk to and occasionally
240 he asks after her he remembers that she has children and sometimes he
241 remembers what they are called [pause] so erm [pause] he's a sweet guy.

I: I wondered what you were thinking then?

245 D: It's funny because I think, we've, our lives have run slightly parallel
246 we've both lived in this area for forty years, there's four years difference in
247 our age, four or five years, we have the same sort of politics, erm it's very

EXPLORATORY CODING

functioning w/ others vs. ?
confused + stuck at home

awareness? "ugly word"
he's demented
self as parts
part of him knows

much better memory than me
sometimes
praise, boasts esteem / credit / worth?

who he remembers

concrete (quick) loop, repetitive
nothing new, no different direction

new conversation outside his wife / thinking
doesn't last long
surprise? unexpected?
likes meeting ppl

delighted someone else to talk to

who he remembers

sweet guy — +ve perceptn

our lives have run parallel

similarities,
things in common
relate to
each other?

Participant Example of Stages of Analysis

| Befriender | Stage 1: Reading and re-reading the transcript. | Stage 2: Initial noting. | Stage 3: Developing emergent themes. | Stage 4: Searching for connections across emergent themes. | Stage 6: Moving to the next case and looking for patterns across cases. |
|------------|---|---|---|--|--|
| Gregory | <p>She has elements of erm [pause] feeling separate from her <i>faith</i>, because she couldn't <i>connect</i> to it, erm she had elements where she felt separate from her <i>family</i> [...] she wasn't involved in any way with her community but she was separate from it anyway [...] and also from herself, in a sense that, she wasn't really sure like what was happening to her. (294-301)</p> <p>We were walking around the room and she was trying to explain the different pictures to me [...] she was giving me like a tour of her room [...] it was really nice [pause] just recollecting, it was almost like this was her kind of mind, and we were just like walking round it. (509-532).</p> | <p>Separate from faith. Separate from family. Separate from community. Separate from herself.</p> <p>Tour of room = walking around mind. Room and belongings = memories and identity.</p> | <p>Separate from everything and everyone</p> <p>A journey to her mind and self.</p> | Rediscovering a lost identity. | <p>Superordinate Theme 3: Core existential experiences.</p> <p>Subordinate theme 3a: Reuniting them with a lost world.</p> |

Prevalence of Themes

| | | Alexander | Bill | Chris | Daphne | Elliott |
|--|--|-----------|------|-------|--------|---------|
| Theme 1: The Person As The Centre | Theme 1a: Putting them first | YES | YES | YES | NO | YES |
| | Theme 1b: Seeing the person past the stereotype | NO | YES | NO | YES | NO |
| | Theme 1c: Valuing the individual | YES | YES | YES | YES | YES |
| Theme 2: A Paradoxical Relationship | Theme 2a: Comparable but indescribable | YES | NO | YES | YES | YES |
| | Theme 2b: Personal but professional | YES | YES | YES | YES | YES |
| | Theme 2c: Two-way but not reciprocal | YES | YES | YES | NO | NO |
| | Theme 2d: Predictable but still uncertain | YES | YES | YES | NO | NO |
| Theme 3: Core Existential Experiences | Theme 3a: Reuniting them with a lost world | YES | NO | YES | YES | YES |
| | Theme 3b: Deeply meaningful experiences | YES | NO | NO | NO | YES |
| | Theme 3c: The essence of human living | YES | YES | YES | YES | NO |

| | | Fraser | Gregory | Harriet | Janie |
|--|--|--------|---------|---------|-------|
| Theme 1: The Person As The Centre | Theme 1a: Putting them first | YES | NO | YES | YES |
| | Theme 1b: Seeing the person past the stereotype | YES | YES | NO | YES |
| | Theme 1c: Valuing the individual | YES | YES | YES | YES |
| Theme 2: A Paradoxical Relationship | Theme 2a: Comparable but indescribable | YES | YES | YES | YES |
| | Theme 2b: Personal but professional | YES | YES | YES | YES |
| | Theme 2c: Two-way but not reciprocal | YES | YES | YES | YES |
| | Theme 2d: Predictable but still uncertain | YES | NO | YES | YES |
| Theme 3: Core Existential Experiences | Theme 3a: Reuniting them with a lost world | NO | YES | YES | YES |
| | Theme 3b: Deeply meaningful experiences | YES | YES | YES | YES |
| | Theme 3c: The essence of human living | NO | YES | YES | YES |

Note: A theme was considered present for a participant if it was identified as a theme in their individual analysis