THE UNIVERSITY OF HULL

Understanding Positive Experiences of Professional Caregivers Who Support People Living with Dementia

being a Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Lucy Bartels, BSc (Hons) Psychology

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I would like to dedicate this research to the professional caregivers who shared their thoughts and feelings about their role with me; I thoroughly enjoyed my time with each of them. Without them this research would not have been possible and I would to thank them for being willing to reflect and be honest about their experiences. I hope I have given them the voice they so deserve.

I would like to acknowledge my research supervisors, Dr Chris Clarke and Dr Emma Wolverson for their continuous, unwavering support. Thank you for being for being so passionate from the very beginning, and helping me realise this project was possible; I really appreciate all the time and effort you have put into this research. Thank you also to Dr Tim Alexander for his knowledge and guidance which has helped me through the research process.

I would also like to thank my amazing family for their love, encouragement and support; I am grateful for all you have done for me. To my Mum and Andy, thank you for everything, I would not be where I am today if not for you both. Finally, thank you to my partner Mark for your patience and love, which has kept me going when I needed it most.
Overview

This portfolio thesis is divided into three parts; a systematic literature review, an empirical paper, and a set of appendices. The thesis as a whole seeks to understand positive experiences of professional caregivers, in order to provide a more holistic understanding of caregiving in residential dementia care settings.

Part one is a systematic literature review which explores and reviews the literature relating to positive and negative aspects of caregiving experienced by professional caregivers in residential dementia care settings. Factors associated with positive and negative experiences of caregiving are also examined. Fourteen papers were identified and reviewed using a narrative synthesis approach; three themes and six subthemes were identified. The findings are considered and discussed in the context of previous literature relating to caregiving in addition to clinical and research implications.

Part two is an empirical paper exploring hope in professional caregivers in residential dementia care settings. The investigation includes the experience of hope, facilitators/barriers of hope and the role of hope in caregiving. Using a constructivist Grounded Theory approach a focus group consisting of six participants was conducted, and purposive theoretical sampling was used to conduct nine individual interviews. Data were analysed using constructivist Grounded Theory and nine categories emerged which were organised into three theoretical concepts. The emergent theory is discussed in the context of previous literature relating to hope and caregiving in addition to clinical and research implications.

Part three is a set of appendices for both the systematic literature review and empirical paper, and includes an epistemological statement and reflective statement.

Total word count: 27,165 (including abstracts, tables and appendices; excluding references)
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Part One: Systematic Literature Review
Positive and negative aspects of caregiving amongst paid dementia care staff in residential settings: A systematic review and narrative synthesis

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This paper is written in the format ready for submission to the Journal of International Psychogeriatrics. Please see Appendix A for the Guideline for Authors

Word count: 5,410 (excluding references and tables)
Abstract

Background

Dementia care requires a resilient skill set of competence and empathy, yet professional caregivers continue to feel undervalued. Attitudes and experiences of professional caregivers are important to consider as they are likely to influence the level and quality of care provided. Whilst the negative psychosocial effects of caregiving have been highlighted, it may be fruitful to consider how such occurrences may be offset by positive experiences. This would in turn allow for a more holistic and balanced role perception, and a more rounded understanding of staff experience could aid care organisations to maintain a high quality of care. Therefore, the aims were to explore and review the literature relating to positive and negative aspects of caregiving in residential dementia care settings and the factors associated with these aspects.

Method

A systematic literature search was conducted using four electronic databases, including PsycARTICLE, PsycINFO, MEDLINE and Web of Science. A narrative synthesis approach was utilised to integrate the findings.

Results

Fourteen papers were incorporated in the review sharing both positive and negative aspects of caregiving. The findings were described by three themes; ‘positive aspects of caregiving’, ‘negative aspects of caregiving’, and ‘personal resources’.

Conclusion

The findings highlight the potential interplay between positive and negative aspects of caregiving amongst paid dementia care staff. The application of a positive psychology perspective to understanding carer well-being, as suggested by the findings, has
important implications for clinical practice and future research aimed at sustaining high quality dementia care.

Keywords: Dementia, professional caregiving, care homes, synthesis, review.
**Introduction**

Up to 75% of people living in care homes have a diagnosis of dementia (Chenoweth *et al.*, 2009) and for these individuals maintaining well-being will depend in part on the quality of care they receive from professional caregivers (see Willemse *et al.* 2015). In the UK, the All-Party Parliamentary Group on Dementia (2009) report stated that dementia care requires a high level of competence, including empathetic and emotional skills. However, the report also asserts that staff continue to be perceived as having low status, and are underpaid and undervalued; ultimately resulting in high staff turnover. The rate of turnover amongst professional caregivers is likely to directly influence the quality of care provided to people living with dementia (Bonner *et al.*, 2009; Coogle *et al.*, 2007).

Professional caregiver well-being and attitudes may be affected by a range of factors, including the care unit size, experience and knowledge related to dementia care (Kada *et al.*, 2009). A recent literature review conducted by Hazelhof *et al.* (2016) sought to provide a detailed understanding of the stress faced by caregivers in the context of ‘challenging behaviour’ in residential homes. The review highlighted aspects such as residents’ behaviour and physical health, as well as less staff experience, younger age, more training and lower seniority level as common factors associated with stress.

Whilst the potential for professional caregiving in dementia to have negative psychosocial effects on staff has been documented (Mackenzie and Peragine, 2003), it is also important consider if and how such experiences might be offset by positive experiences, in order to provide a more holistic view of the role. In respect to family caregivers in dementia, the complexity of the caregiving relationship has been increasingly acknowledged, with positive experiences existing alongside the negative. Positive aspects of caregiving (PAC) can include a sense of competence (Cohen *et al.*, 2009).
The Positive Aspects of Caregiving Questionnaire (PACQ) has recently been validated for use with family caregivers, and is based on the idea that although negative factors can be present, caregiving can also yield positive aspects (Abdollahpour et al., 2017). Such developments reflect the application of Positive Psychology (PP) concepts to understanding caregiving. Recent PP perspectives recognise how both negative and positive experiences co-exist (Wong, 2011) and acknowledge the dynamic interplay between both negative and positive psychological processes. They also consider how individuals might attempt to find ways to overcome challenges in order to flourish (Lomas and Ivtzan, 2015).

Whilst a growing body of literature indicates that PAC play an important role in the well-being of family caregivers, the extent to which paid dementia care staff also experience and benefit from PAC has so far been unclear. To date, no review has been undertaken of literature relating to factors that may be associated with both positive and negative aspects of caregiving amongst dementia staff. Typically, research has focused on negative aspects of caregiving, with little emphasis on exploring a more balanced view (e.g. Schaefer and Moos, 1993). Professional caregiver attitudes are associated with stress, ultimately impacting job commitment, therefore it is vital turnover is reduced. A thorough understanding of these attitudes could aid care home managers retain a high quality of care (Coogle et al., 2007). As such, this systematic review aimed to examine factors related to both positive and negative aspects of caregiving in residential dementia care settings, in order to explore a balanced view of caregiving.

The questions which this systematic literature review sought to address were:

1. What positive and negative aspects of caregiving have been investigated for dementia care staff supporting individuals living with dementia?
2. What factors, explored within the literature to date, are associated with positive and negative experiences of professional caregiving in dementia?

Method

Search Terms

A systematic search was completed in May 2017, using four electronic databases: PsycARTICLE, PsycINFO, MEDLINE and Web of Science. These databases were chosen to yield papers published in multiple fields including psychology and nursing. Additionally, relevant authors were contacted and reference lists of included studies searched to determine any further pertinent papers.

Search terms were selected on the basis of scoping previous literature reviews that sought to review staff or family experiences of caregiving in dementia or other chronic conditions (e.g. Hazelhof et al., 2016; Spector et al., 2016). The search terms were divided into four categories:

1. Terms related to dementia: ‘dementia’ or ‘Alzheimer’s’.
2. Terms to access information about professional caregivers: ‘staff’ or ‘professional caregiver’ or ‘dementia carer’ or ‘nursing’
3. Terms related to positive aspects: ‘positive’ or ‘quality of life’ or ‘professional quality of life’ or ‘compassion satisfaction’ or ‘satisfaction’ or ‘gratitude’ or ‘gratification’ or ‘benefit’ or ‘well-being’ or ‘reward’ or ‘meaning’.
4. Terms related to negative aspects: ‘negative’ or ‘burden’ or ‘burnout’ or ‘compassion fatigue’ or ‘exhaustion’ or ‘job strain’.

Truncations of search terms (e.g. dement* or well?being) were utilised to allow a greater number of papers to be identified. The Boolean phrase N3 was also utilised to
ensure papers focused on dementia caregiving were retrieved. Additional filters were applied to ensure retrieval of papers written in the English Language only, published from January 1997 – May 2017 (following a large shift in caregiving approaches towards ‘person-centred’ care; Kitwood, 1997), and peer-reviewed only.

**Inclusion Strategy**

Papers were chosen for review if they met the following criteria:

- The study included professional caregivers having contact with residents living with dementia, for example healthcare assistants, nursing staff, etc. The literature to date has not tended to distinguish by job role and therefore it was not possible to do so in this review.
- The study aimed to explore how professional caregivers experienced their role and/or aspects of providing care to people living with dementia.
- The study aimed to ascertain factors predictive of, or associated with their experiences.
- The study included data collected from residential/nursing homes (long-term facilities).
- The study used a quantitative self-report instrument to measure staff experience and/or attitudes to allow investigation of attitudes, experiences and common associated factors.
- The study was empirical, as opposed to a literature review.
- The study was written in the English Language.
- The study was published in a peer-reviewed journal to ensure rigour and quality.

**Exclusion Strategy**

Papers were excluded for review if they:


• Aimed to explore the effectiveness of an intervention for staff or residents due to the large variety of incomparable interventions utilised across research.

• Did not focus on professional caregivers e.g. focussed on family or spousal caregivers.

• Only collected data from acute care settings/community living as opposed to residential/nursing homes due to the variance in and purpose of staff involvement.

• Did not use a quantitative measure relating to staff experience and/or attitudes as this would not allow investigation of attitudes and experiences, or possible common associated factors.

• The article was a literature review or discussion paper.

**Quality Assessment**

As no existing checklist was identified which met the needs of the current review, a bespoke checklist was developed to assess methodological quality of included studies (Appendix C). The checklist was adapted from two existing methodological quality checklists previously used in healthcare research. The first measure was the ‘Quality Appraisal Checklist – Quantitative Studies Reporting Correlations and Associations’ developed by the National Institute for Health and Care Excellence (NICE; 2012a), which included questions relating to participants, outcome measures, precision of association and generalisability. Various questions relating to the effectiveness of interventions were removed to reflect the exclusion criteria of the review. However, questions relating to overall quality such as defined purpose and research design, rigor of data analysis, proposed findings and conclusions were absent from this checklist. To address this, various questions relating to these aspects were extracted from the ‘Quality Appraisal Checklist – Qualitative Studies’ developed by NICE (2012b). As no
qualitative data were present in the studies included, questions directly relating to a qualitative study were not used.

Initially, the first author assessed the methodological quality of each paper using the checklist, followed by the independent researcher randomly selecting and assessing a subset of papers. Numerical scores applied to each section of the checklist (zero = poor, one = adequate and two = good), were summed and converted to a percentage rating of overall quality. Minor discrepancies arose during this process, for example questions relating to overall rigour and clarity of the study. These scores were discussed and debated in regard to the rationale for why particular scores were chosen, until a final consensus was reached. The results generated by the quality assessment were not used as part of the inclusion/exclusion criteria.

**Data Synthesis**

A data extraction tool was created to capture relevant information from each paper (Appendix B).

Although all papers included in the review were of a quantitative design, significant heterogeneity existed with respect to measures and this precluded the use of meta-analysis to summarise and integrate findings. Thus, results were summarised using narrative synthesis, which allowed for the emergence of common concepts in the literature and the consequent construction of an integrated synthesis of relevant findings with respect to positive and negative aspects of professional caregiving. In line with Popay *et al.* (2006), data synthesis proceeded through four key stages: generation of appropriate search terms to ensure retrieval of relevant papers (whilst utilising the inclusion/exclusion criteria); utilisation of the data extraction tool to extract necessary information; utilisation of quality ratings to assess rigorousness; and identification of
positive/negative aspects of caregiving and discrepancies/similarities among related factors.

Results

Identification of Relevant Studies

Ten papers met the inclusion criteria following the database search, and four more papers were included following a manual search of reference lists. No additional papers were identified following contact with relevant authors. The selection process is outlined in Figure 1.
Table 1 details the main characteristics of the included studies along with the relevant findings extracted for analysis. Numbers of participants varied and ranged from 18 (Jenkins and Allen, 1998) to 1147 (Schmidt et al., 2014). In total 3845 people contributed, who were predominantly female with ages ranging from 16 to 67 years old. Two studies did not report the number of facilities data was collected from (Lee et al.,
but the remaining studies ranged from 2 facilities (Jenkins and Allen, 1998) to 40 (Edvardsson et al., 2009; Schmidt et al., 2014), with an overall total of 206 facilities.

Only four studies deliberately set out to explore positive aspects (Drebing et al., 2002; Hughes et al., 2008; Moyle et al., 2011; Mullan and Sullivan, 2016) which included job satisfaction (Brodaty et al., 2003; Moyle et al., 2011; Zimmerman et al., 2005), job commitment (Drebing et al., 2002), self-efficacy, and knowledge or confidence (Duffy et al., 2009; Hughes et al., 2008; Mullan and Sullivan, 2011). Negative aspects included job strain (Brodaty et al., 2003; Edvardsson et al., 2009), stress (Testad et al., 2010; Zimmerman et al., 2005), and burnout (Duffy et al., 2009; Jenkins and Allen, 1998; Kimura et al., 2011; Schmidt et al., 2014).

A range of outcome measures were utilised in the studies, with no two studies utilising an identical set of measures. The Approaches to Dementia Questionnaire (ADQ), which is designed to assess attitudes towards dementia, incorporating both hope and person-centred factors (Lintern, 2001), was employed in four studies (Moyle et al., 2011; Mullan and Sullivan, 2016; Spector and Orrell, 2006; Zimmerman et al., 2005). The Maslach Burnout Inventory (MBI; Maslach et al., 1996), whereby burnout is considered to be a combination of emotional exhaustion, depersonalisation and reduced personal accomplishment, was employed in three studies (Duffy et al., 2009; Jenkins and Allen, 1998; Kimura et al., 2011). The Staff Experience of Working with Demented Residents Questionnaire (SEWDRQ; Astrom et al., 1991), includes items relating to satisfaction and relationships with other caregivers and residents, and was employed in two studies (Moyle et al., 2011; Zimmerman et al., 2005). The remaining measures were only utilised once across the set of papers (see Table 1).
Table 1. A summary of the included papers

<table>
<thead>
<tr>
<th>Author, Date &amp; Country</th>
<th>Aims</th>
<th>Number of Participants &amp; Care Facilities</th>
<th>Caregiving Measures</th>
<th>Positive and Negative Factors Investigated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brodaty et al. (2003), Australia</td>
<td>To investigate attitudes of staff towards residents, job strain and satisfaction.</td>
<td>253 caregivers, 12 facilities</td>
<td>• Swedish Strain in Nursing Care Assessment Scale (Hallberg and Norberg, 1995) • Swedish Satisfaction with Nursing Care and Work Assessment Scale (Hallberg et al., 1994)</td>
<td>• Positive factors: job satisfaction • Negative factors: job strain</td>
</tr>
<tr>
<td>Drebing et al. (2002), USA</td>
<td>To identify factors which predict job and career commitment.</td>
<td>77 caregivers, 6 facilities</td>
<td>• 4 items from the Boston University Alzheimer’s Disease Core Centre (BU ADCC) to measure job and career commitment</td>
<td>• Positive factors: job commitment, career commitment, personal benefits of caregiving,</td>
</tr>
</tbody>
</table>
• 6-item scale adapted to measure personal benefits of caregiving such as increased awareness of inner strengths and personal growth (Pruchno et al., 1990)

• Bespoke non-standardised Likert scale items to measure attachment to residents and families developed for the study

• Professional caregiver burden index (PCBI) (McCarty and Drebing, 2002)

• Grief Resolution Index (GRI) (Redmondet and Hansson, 1987)

• Negative factors: burnout and grief

Duffy et al. (2009), UK

To explore burnout in staff and examine roles of 61 caregivers and 7 facilities

• MBI (Maslach et al., 1996)

• Jeffcott Reciprocity Questionnaire (Jeffcott, 2002)

• Positive factors: reciprocity, self-relationships with residents and their families
<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Methodology</th>
<th>Positive factors</th>
<th>Negative factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edvardsson <em>et al.</em> (2009), Sweden</td>
<td>To identify predictors of job strain. 344 caregivers, 40 facilities</td>
<td>Inventory of Geriatric Nursing Self-Efficacy (Mackenzie and Peragine, 2003) The Occupational Commitment Questionnaire (Mowday <em>et al.</em>, 1979) Demand and control questionnaire (Karasek and Theorell, 1990) Perceived unit caring climate and own knowledge in caregiving determined using two bespoke non-standardised scales designed for the study</td>
<td>Reciprocity, self-efficacy and organisational factors.</td>
<td>Negative factors: job strain burnout</td>
</tr>
<tr>
<td>Hughes <em>et al.</em> (2008), UK</td>
<td>To examine the degree of knowledge and confidence in staff and identify factors 254 caregivers, 30 facilities</td>
<td>Knowledge of dementia care and confidence assessed by rating the level of expressed competence in managing</td>
<td></td>
<td>Positive factors: perceived unit caring climate and knowledge in caregiving</td>
</tr>
</tbody>
</table>
which contribute to confidence.

| **Jenkins and Allen (1998), UK** | To explore the relationship between staff burnout/distress, perceived involvement in decision-making and the quality of care provided. | 18 caregivers | • MBI (Maslach *et al.*, 1996)  
• Perceived Involvement Personal Questionnaire (PIPQ) (Garety and Morris, 1984)  
• Quality of Interactions Schedule (QUIS; Dean *et al.*, 1993) and the time-sampling method developed by Garety and Morris (1984) | Positive factors: perceived involvement and quality/quantity of staff-resident interactions | 2 facilities |

<p>| <strong>Kimura <em>et al.</em> (2011), Japan</strong> | To clarify relationship between burnout and the characteristics of mental health of caregivers. | 107 caregivers | • Survey measuring present state of health, perceived ill health, job stress, problems at work and burden in care developed for the study | Positive factors: health and well-being | 12 facilities |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Number of</th>
<th>Number of</th>
<th>Tool(s)</th>
<th>Positive aspects</th>
<th>Negative factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee <em>et al.</em></td>
<td>To examine attitudes and how the presence of specialised care units may affect staff.</td>
<td>1047</td>
<td>unknown</td>
<td>Questionnaire items developed for the study relating to: current state of dementia care in workplace, opinion regarding dementia care in general, importance of certain behaviours, dementia symptoms</td>
<td>Positive aspects: attitudes, job commitment</td>
<td>Negative factors: job stress, problems at work, burden in care and burnout</td>
</tr>
<tr>
<td>(2013), Hong Kong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moyle <em>et al.</em></td>
<td>To determine care staff attitudes to dementia, assess levels of job satisfaction and explore how these attitudes</td>
<td>49</td>
<td>4</td>
<td>ADQ (Lintern, 2001)</td>
<td>Positive factors: attitudes, satisfaction</td>
<td></td>
</tr>
<tr>
<td>(2011), Australia</td>
<td></td>
<td></td>
<td></td>
<td>SEWDRQ (Astrom <em>et al.</em>, 1991)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
and experience may relate to each other.

| **Mullan and Sullivan (2016), Australia** | To clarify relative importance of staff factors associated with a sense of competence. | 61 caregivers | • Sense of Competence in Dementia Care (SCIDS) (Schepers et al., 2012)  
• ADQ (Lintern, 2001)  
• Dementia Knowledge Assessment Tool Version Two (DKAT2) (Toye et al., 2014) | • Positive factors: sense of competence, attitudes and knowledge |
| **Schmidt et al. (2014), Germany** | To investigate satisfaction with quality of care and its impact on general health, burnout and work ability utilising a longitudinal design. | 1147 caregivers, 40 facilities | • Questionnaire based on the questionnaires of the European nurses’ early exit (NEXT) study covering aspects of work and health outcomes (Hasselhorn et al., 2003)  
• Satisfaction with the quality of care (Schmidt et al., 2011) | • Positive factors: satisfaction, general health, work ability  
• Negative factors: burnout |
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Objective</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spector and Orrell (2006), UK</td>
<td>To compare the quality of life of people living with dementia as assessed by the individuals and care staff, and possible factors associated with discrepancies.</td>
<td>76 caregivers, 9 facilities</td>
<td>ADQ (Lintern, 2001)</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Participants</td>
<td>Measures</td>
</tr>
<tr>
<td>------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------</td>
<td>--------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Testad et al.</td>
<td>To investigate the association of psychosocial factors and resident factors with stress in care staff.</td>
<td>197 caregivers, 13 facilities</td>
<td>General Nordic Questionnaire for Psychosocial and Social Factors at Work (QPSNordic) (Dallner et al., 2000)</td>
</tr>
<tr>
<td>Norway, 2010</td>
<td></td>
<td></td>
<td>Perceived Stress Scale (PSS) (Cohen et al., 1983)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hopkins Symptoms Check List (HSCL) (Strand et al., 2003)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ursin Health Inventory (Ursin et al., 1988)</td>
</tr>
<tr>
<td>Zimmerman et al.</td>
<td>To explore the dementia-related attitudes of nursing staff, as well as their work stress and satisfaction.</td>
<td>154 caregivers, 31 facilities</td>
<td>ADQ (Lintern, 2001)</td>
</tr>
<tr>
<td>USA, 2005</td>
<td></td>
<td></td>
<td>Work Stress Inventory (Schaefer and Moos, 1993)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>SEWDRQ (Astrom et al., 1991)</td>
</tr>
</tbody>
</table>
Methodological Quality

Methodological quality ratings assigned to papers are shown in Table 2. Quality ratings range from 69% to 92%, meaning all studies were considered to be of relatively good quality. A detailed description of quality assessment can be found in Appendix D.

**Table 2.** A summary of the methodological quality ratings of each included study

<table>
<thead>
<tr>
<th>Study</th>
<th>Quality Rating (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brodaty et al. (2003)</td>
<td>81</td>
</tr>
<tr>
<td>Drebing et al. (2002)</td>
<td>85</td>
</tr>
<tr>
<td>Duffy et al. (2009)</td>
<td>88</td>
</tr>
<tr>
<td>Edvardsson et al. (2009)</td>
<td>73</td>
</tr>
<tr>
<td>Hughes et al. (2008)</td>
<td>85</td>
</tr>
<tr>
<td>Jenkins and Allen (1998)</td>
<td>69</td>
</tr>
<tr>
<td>Kimura et al. (2011)</td>
<td>85</td>
</tr>
<tr>
<td>Lee et al., (2013)</td>
<td>85</td>
</tr>
<tr>
<td>Moyle et al. (2011)</td>
<td>92</td>
</tr>
<tr>
<td>Mullan and Sullivan (2016)</td>
<td>81</td>
</tr>
<tr>
<td>Schmidt et al. (2014)</td>
<td>81</td>
</tr>
<tr>
<td>Spector and Orrell (2006)</td>
<td>81</td>
</tr>
<tr>
<td>Testad et al. (2010)</td>
<td>77</td>
</tr>
<tr>
<td>Zimmerman et al. (2005)</td>
<td>92</td>
</tr>
</tbody>
</table>

Variety was evident across individual items of the quality assessment tool, including theoretical approach and recruitment of participants; some aspects were adequate
whereas other aspects were less satisfactory. Further, only two studies (Mullan and Sullivan, 2016; Schmidt et al., 2014) reported psychometric properties for the measures adequately. Remaining studies did not report on these aspects or only discussed some measures in detail. Data analysis was judged to be systematic and rigorous for all but one of the studies, (Kimura et al., 2011) which partially fulfilled the criteria. The majority of studies presented their findings clearly and coherently; findings were relevant to the aims of each study.

**Synthesis of Findings**

An integrated synthesis of the findings of included studies identified three themes and six sub-themes. Table 3 shows the studies associated with each theme and sub-theme.

**Table 3. Themes and subthemes identified during analysis of the data**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Aspects of Caregiving</td>
<td>Satisfaction</td>
<td>Brodaty et al. (2003); Moyle et al. (2011);</td>
</tr>
<tr>
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**Theme one: Positive aspects of caregiving**

The first theme relates to the positive aspects of caregiving in residential dementia care settings, such as job satisfaction, job commitment and career commitment.

*Satisfaction*

Five studies investigated job satisfaction, with minor differences in findings. There was variation in how job satisfaction was measured, potentially based on different conceptualisations of satisfaction, which could have contributed to discrepancies found. Brodaty et al. (2003), Moyle et al. (2011), and Zimmerman et al. (2005) found satisfaction to be generally high, with positive statements relating to job satisfaction being completely or partly endorsed by 90% of their participant group (Brodaty et al., 2003). Resident contact subscales were generally found to produce the highest satisfaction score (Moyle et al., 2011; Zimmerman et al., 2006) and satisfaction with the physical design of the work environment the lowest score (Moyle et al. 2011). Schmidt et al. (2014) examined the overall level of group satisfaction with the care of residents and whether this could be sustained over the course of two years. In 2007, 59% of the
participant group were satisfied and 41% dissatisfied, in 2009 65% were satisfied and 35% dissatisfied, indicating increases in job satisfaction over time; it is unclear why this change emerged. The authors suggest this could be a result of increased public and professional discussions regarding quality of care, and the implementation of National care development policies in Germany in 2008, causing an increased awareness of person-centred care. Satisfied caregivers also reported the highest overall ratings of general health and work ability, but even where satisfaction was sustained, ratings of general health and work ability significantly declined. For caregivers who were dissatisfied, reports of general health and work ability were generally lower, with 92% of caregivers feeling stressed as a result of lower general health and work ability (Schmidt et al., 2014).

The older age of participants was found to be a predictor of satisfaction in two studies (Brodaty et al., 2003; Zimmerman et al., 2005), although Schmidt et al. (2014) reported no significant correlation between satisfaction and socio-demographic factors, and length of experience in care was not found to be associated with satisfaction by Brodaty et al. (2003). The discrepancy regarding age could be a reflection of the differences in measures utilised; although psychometric properties were discussed to an extent in each study, Schmidt et al. (2014) measured satisfaction using a single item, which may have decreased validity.

In terms of attitudes towards dementia and satisfaction, discrepancies were evidenced. Brodaty et al. (2003) and Moyle et al. (2011) found person-centred and hopeful attitudes towards dementia to be positively correlated with job satisfaction. Zimmerman et al. (2005) and Moyle et al. (2011), utilising the same satisfaction measure, also found person-centred care to be positively correlated with satisfaction (Moyle et al., 2011).
However, hopefulness was not found to be associated with job satisfaction by Spector and Orrell (2006), who used the same attitudes measure.

Commitment to professional caregiving

Three studies investigated job commitment to the caregiving role, encompassing commitment to the current role and to caregiving as a career. Varying measures were utilised.

Duffy et al. (2009) found job commitment to be moderate, and Drebing et al. (2002) found 50% of a participant group were thinking of leaving their post and 25% were actively searching for a new job. Lee et al. (2013) did not find age, gender, marital status, education and total hours to be related. However, Drebing et al. (2002) found that more time spent with residents, being in the role for more than ten years, and having an attachment with residents’ families were linked with higher levels of dedication. Specifically, having a specialist dementia unit was found to be connected to a sense of loyalty for the current job role (Lee et al., 2013). A lack of commitment was associated with higher levels of burnout, according to Drebing et al. (2002) and Duffy et al. (2009).

Both Drebing et al. (2002) and Lee et al. (2013) reported career loyalty to be moderately high, with 75% and 90% of two participant groups agreeing they would stay in professional caregiving for their remaining career. Similarly to job commitment, age, gender, marital status, education and length of time in the role was not found to be related to career commitment (Lee et al., 2013). More time with residents, higher income, working in a non-profit home, intrinsic rewards (such as personal growth), and interestingly, higher levels of grief were found to be associated with higher levels of career commitment, according to both Drebing et al. (2002) and Lee et al. (2013).
Lower levels of career commitment were also associated with higher levels of burnout, according to Drebing et al. (2002).

**Theme two: Negative aspects of caregiving**

The second theme relates to negative aspects of caregiving in residential dementia care settings, including the experience of burnout, and stress and strain.

**Experience of burnout**

Three studies investigated burnout as their main aim (Duffy et al., 2009; Jenkins and Allen, 1998; Kimura et al., 2011), where burnout was defined as a combination of increased emotional exhaustion and depersonalisation, and decreased personal accomplishment; whereas one study investigated burnout as an adjunct factor (Schmidt et al., 2014). Duffy et al. (2009) reported 76% of 61 professional caregivers were emotionally exhausted and 43% felt depersonalised, however 75% of the total questioned reported feeling accomplished in their work at that time. Further, Kimura et al. (2011) found 53% of 107 professional caregivers were experiencing burnout at the time they participated in the study.

Kimura et al. (2011) report that positive well-being, mental mastery, confidence, congruence between expectation and achievement, and emotional support were associated with lower levels of burnout. Schmidt et al. (2014) also found higher levels of job satisfaction were related with lower levels of burnout. Additionally, Duffy et al. (2009) found significant negative correlations between age and emotional exhaustion and depersonalisation. Reciprocity with residents (Duffy et al., 2009), and the quality and quantity of staff-resident interactions (Jenkins and Allen, 1998) was not found to be associated with emotional exhaustion and depersonalisation. Personal accomplishment was found to be associated with quantity of staff-resident interactions by Jenkins and
Allen (1998), yet was not related to the quality of these interactions. Moreover, Duffy et al. (2009) reported personal accomplishment was negatively correlated with number of contracted hours and reciprocity with the organisation. Duffy et al. (2009) also reported higher levels of self-efficacy were associated with lower levels of burnout.

*Stress and strain*

Stress and strain were examined as adjunctive factors rather than as main aims in three of the fourteen studies, with different instruments utilised. Edvardsson et al. (2009) investigated job strain and aspects professional caregivers believe are involved in their roles. The majority of professional caregivers believed their roles involved learning new information, skills, and creativity; they also believed they had freedom to decide how and what to accomplish in their work. However professional caregivers also felt their role required them to apply disproportionate levels of effort, work intensely and quickly, and manage conflicting demands while having insufficient time to accomplish tasks. Furthermore, Zimmerman et al. (2005) found stress to be relatively high, particularly in relation to caring for residents.

Having knowledge of dementia, receiving training, caregiver gender, and presence of resident agitation were not found to be related to job strain/stress by Edvardsson et al. (2009). However, disparity occurred in regard to work experience; both Edvardsson et al. (2009) and Testad et al. (2010) found no association between work experience and stress/strain, whereas Zimmerman et al. (2005) reported less work experience was associated with higher levels of stress. Edvardsson et al. (2009) and Testad et al. (2010) did not report psychometric properties of measures used, whereas Zimmerman et al. (2005) reports good psychometric properties, and therefore may hold higher validity. There was also discrepancy as to whether levels of education were associated with
stress and strain; Edvardsson et al. (2009) found lower education to be related to higher levels of job strain, whereas Testad et al. (2010) did not find an association. Edvardsson et al. (2009) found higher work demands, less control at work, a negative perceived caring climate and being younger were associated with stress and strain. Testad et al. (2010) also found less work control, shift work, and being younger tended to be associated with stress and strain. When professional caregivers perceived sparse opportunity to discuss ethical conflicts or difficulties in their role, higher levels of job strain were found by Edvardsson et al. (2009). Further, Zimmerman et al. (2005) reported that when caregivers held negative views about their colleagues, workload and physical design of their workplace, higher levels of stress were found.

**Theme three: Personal resources**

The third theme relates to the personal resources of professional caregivers that may help foster positive experiences of caregiving.

*Confidence and self-efficacy*

Confidence in caregiving and self-efficacy were investigated in four studies, but there was variation in how these aspects were measured, and potentially based on different conceptualisations of confidence and self-efficacy. It is also important to reflect upon the possibility that professional caregivers may have been unlikely to share lack of confidence when participating in a study.

Confidence and self-efficacy were considered in the context of managing resident ‘behaviour’; with every caregiver of a participant group describing residents as exhibiting ‘challenging behaviour’, according to Duffy et al. (2009), who reported high self-efficacy scores for managing challenges. In contrast Lee et al. (2013) found that 79% of a group of professional caregivers reported difficulties with managing
‘challenges’. Discrepancies in quality ratings were evident in the use of measures; strong psychometric properties were reported by Duffy et al. (2009), whereas the measure utilised by Lee et al. (2013) was developed for the study; with no existing research regarding reliability and validity; this could account for the discrepancy.

Gender, type of role and presence of a specialist dementia unit were not found to be linked with self-efficacy by Lee et al. (2013), and training, holding formal qualifications and dementia knowledge were not found to be associated with a sense of competence by Mullan and Sullivan (2016). In contrast, more training, holding formal qualifications and higher dementia knowledge levels were found to be connected to higher confidence by Hughes et al. (2008). Additionally, holding the position of a senior level carer was found to be associated with higher confidence by Hughes et al. (2008). Conversely, Lee et al. (2013) reported that being a senior level carer was found to be associated with low self-efficacy in ‘managing residents’. Despite gaining a lower quality score overall, Mullan and Sullivan (2016) reported psychometric properties of the measures utilised whereas Hughes et al. (2008) utilised a new measure, and psychometric properties were not reported; therefore, the findings of Mullan and Sullivan (2016) may hold more validity.

**Hopeful and person-centred attitudes**

Of the fourteen studies, three examined attitudes towards dementia; specifically utilising the ADQ (Lintern, 2001). Overall, attitudes were relatively positive on the ADQ total and the subscales; person-centeredness and hopefulness, for each study. Both Moyle et al. (2011) and Zimmerman et al. (2005) found positive attitudes to be more evident in the person-centred subscale in contrast to the hopefulness subscale.

According to both Moyle et al. (2011) and Zimmerman et al. (2005) satisfaction with feedback at work and resident contact was positively correlated with positive attitudes
towards dementia, particularly the person-centred subscale. However, Spector and Orrell (2006) did not find job satisfaction to be associated with hopeful attitudes towards dementia. This discrepancy could have arisen from the measure utilised to determine satisfaction; Moyle et al. (2011) and Zimmerman et al. (2005) utilised the same measure and reported adequate psychometric properties whereas Spector and Orrell (2006) applied a separate measure and did not discuss psychometric properties. Zimmerman et al. (2005) found professional caregivers who had more experience and worked in a setting with an older facility (as opposed to newly built facilities) were less likely to hold hopeful and person-centred attitudes. Caregivers who had higher levels of education and attended more training were more likely to hold person-centred attitudes. Interestingly, when examining resident-assessed quality of life, Spector and Orrell (2006) discovered higher ratings were associated with higher levels of hopefulness held by staff.

Discussion

Overview of Findings

This review aimed to collate the positive and negative aspects of caregiving amongst dementia care staff and investigate factors associated with each. It is important to investigate positive and negative factors in parallel to provide a holistic perspective of professional dementia caregiving; existing empirical work has not tended to take this approach.

It is difficult to draw firm conclusions from existing literature concerning factors associated with positive and negative aspects of caregiving. Considerable discrepancies were found in the results which have been discussed in the context of potential quality
differences between studies. It is challenging to ascertain plausible hypotheses relating to these aspects due to the large variance in measures and disparities in previous literature. For example, being a senior level carer was aligned with higher levels of confidence, however, Hazelhof et al. (2016) report staff training and nursing levels were common factors associated with stress. The development of standardised PAC measures may help further our understanding of professional caregiving and potentially reduce inconsistencies.

Despite various positive aspects found in the literature, the majority of studies included in this review set out to study negative aspects of caregiving. It is possible the application of a PAC model from family caregiving may allow for the furthering of balanced empirical work in this area. Carbonneau et al. (2010) developed a conceptual framework of positive aspects of family caregiving in dementia which proposes that caregiver wellbeing is determined by a number of factors, including self-efficacy, a sense of accomplishment and quality of care-recipient/caregiver relationship. This review potentially supports the application of this conceptual framework, and similarly highlights self-efficacy as a positive aspect of care relevant to professional caregivers. A sense of accomplishment is also indicated as significant in this framework; an aspect yet to be explored in the professional caregiving literature. The importance of multiple staff-resident interactions was highlighted in this review, although the framework proposed by Carbonneau et al. (2010) indicates it is the quality of this relationship which influences caregiver well-being, highlighting a possible discrepancy.

A further model which could be of relevance in developing research and understanding in this area, is the stress-coping model for family caregivers supporting people living with dementia proposed by Sorensen and Conwell (2011). Their model acknowledges
how socio-demographic characteristics may influence caregiver outcomes. Such factors were investigated in this review, including age, gender, level of education and work experience. However, findings in this review relating to age, level of education and work experience were inconclusive. The model also describes primary and secondary stressors that may influence family caregiver outcomes. Primary stressors include problems directly related to caregiving; the results of this review also identified primary stressors such as burnout. Secondary stressors include strains faced outside of the caregiving role, such as financial strain and social isolation. These were not included in this review, and remain an aspect to be explored. The model also proposes that outcomes are moderated by factors such as a sense of competence and self-efficacy, aspects which were found to have relevance in this review. An additional set of personal resources indicated for professional caregivers were hopeful and person-centred care attitudes, which may further impact professional caregiver outcomes. Whilst both caregiving models may have some relevance for professional caregivers, and the development of more balanced empirical research in this area; significant contextual differences such as pre-existing relationships need to be considered and may limit their relevance.

The exploration of personal resources in the literature, such as caregiver attitudes has been limited, and had divergent findings, yet it is important to consider the implications of these attitudes for care-recipients. Provision of high quality care may directly impact the quality of life for residents; increasing interactions which acknowledge a residents’ need for attachment may be particularly important. (Willemse et al., 2015). Kokkonen et al. (2014) found the likelihood of social engagement between professional caregivers and residents increased when caregivers held more hopeful and person-centred attitudes.
Consequently, it can be hypothesised that particular attitudes of professional caregivers are significant, and can impact the quality of care provided.

**Limitations**

The first limitation of this review relates to the current literature base. The literature is biased towards more negative aspects of caregiving and there are no standardised PAC measures validated for professional caregivers, resulting in a limited understanding to date of aspects such as job satisfaction and self-efficacy.

Moreover, there was a large range of participant numbers and facilities across the studies; and small numbers of participants may have resulted in decreased validity.

There is potential for vast differences as a result of location; for example, staff training, available resources and staff entry level requirements. Although participants in each study had a clinical role, there were a number of different caregiving roles, including nursing staff and healthcare assistants. Social desirability is also important to reflect upon in the caregiving context.

All but one of the studies were cross-sectional; this will have resulted in limited understanding of caregiving in a changing social context. Additionally, direction of causality may be an issue within a review with predominantly correlational studies; a correlation does not necessarily indicate change in the first variable is the cause of change in the second, rather it is possible the causal flow is reversed (Edwards and Bagozzi, 2000).

Further, although careful consideration was given when selecting appropriate search terms, upon reflection, the addition of the term ‘stress’ may have yielded additional
relevant papers. However, papers relating to stress and strain were found via the search terms selected, minimising the risk of overlooking pertinent papers.

**Implications**

An increased awareness of professional caregivers’ experiences within residential care settings is important, particularly for care home managers. Problems with staff recruitment and retention are valid issues to address, particularly given the difficult working context and unique stressors. Further research in this area could potentially help to target professional caregivers who are likely to experience burnout and implement interventions to prevent this. Such interventions could focus on increasing self-efficacy, confidence and caregivers’ sense of competence (Van der Lee et al., 2015), for example by providing supervision. Providing emotional support and increased support from management (Jeon et al., 2012) may also prevent burnout. The findings of this review were inconclusive in regard to training, however a review conducted by Spector et al. (2016) on the effectiveness of training cites the importance of addressing organisational factors as a barrier to change.

Further implications include interventions which promote positive aspects of caregiving, rather than prevention of negative aspects. The link between person-centred and hopeful attitudes with resident outcomes is an emerging area of research with significant implications. Maximising staff-resident interactions, for example by introducing protected time for this, could increase such attitudes. Zimmerman et al. (2005) suggest prioritising person-centred care training could also address this issue, particularly when caregivers perceive themselves as well trained in dementia care.
Conclusion

In summary, the present review, despite some methodological issues, offers an interesting insight into professional caregiver’s experiences and possible factors associated with these. It is important to consider positive aspects alongside negative aspects of professional caregiving, not only for the staff members, but for care-recipients whose lives are affected by the care they receive. Careful consideration of potential future research studies and implementation of viable interventions in care homes are vital for the well-being of professional caregivers, those they care for who are living with dementia, and their respective families.

Conflicts of interest

None.

Description of authors’ roles

Development of the design of the study, conduction of data collection, analysis of data and writing of the paper was undertaken by L. Bartels. C. Clarke and E. Wolverson supervised the process, assisting in the development of the search strategy, design, analysis and preparation of the final paper.
References


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Part Two: Empirical Paper
Hope in Professional Caregivers Working in Residential Dementia Care Settings:  
A Grounded Theory Study

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This paper is written in the format ready for submission to Aging & Mental Health.
Please see Appendix E for the instructions for contributors.

Word count: 5,477 (excluding references and tables)
Abstract

Objectives

Hope may help professional dementia caregivers provide a higher quality of care and foster better relationships with residents and their families. Research conducted with caregivers indicates an important correlation between levels of hope and resident assessed quality of life. To date research investigating how professional dementia caregivers foster and maintain their hope has been limited. The research questions therefore included; how do dementia care staff foster, sustain and experience hope, what are the facilitators/barriers of hope, and how does experience of hope facilitate quality of care.

Method

Using a constructivist Grounded Theory approach, a focus group including six participants was conducted, with purposeful theoretical sampling used to conduct a further nine individual interviews. Interviews were analysed using Charmaz’s Grounded Theory methodology to construct an emergent theory.

Results

Nine categories emerged and were organised into three theoretical concepts; contextual, relational and individual factors. A model is presented to describe the emergent theory and to demonstrate the dynamic balance between different factors. Categories included uni-directional factors which acted to facilitate or hinder hope, and bi-directional factors that served to influence and maintain hope.
Conclusions

Hope may assist caregivers to provide person-centred dementia care, meet resident needs and work effectively within a team. These findings have significant implications for improving the quality of care provided in residential dementia care settings.

Keywords: Dementia, professional caregivers, hope, grounded theory
Introduction

Whilst there is no agreed definition or theory of hope, two prominent psychological models have been proposed and examined empirically. A cognitive model proposed by Snyder (2002), Hope Theory, contains two mechanisms: pathways and agency thinking. This suggests hope is the perception of one’s own capability to create pathways to desired goals, and the motivation to utilise these pathways. In contrast, hope has also been defined by Dufault and Martocchio (1985) in relational terms as a dynamic life force characterised by an expectation one will achieve something valued. This conceptualisation makes a distinction between particularised hope; attainment of specific goals, and generalised hope; an inner intangible experience of hope. There is consistency across definitions of the power of hope as a transformational force and its therapeutic value.

Hope in Caregiving

Existing literature suggests hope, as defined by Dufault and Martocchio’s (1985), has a positive impact on professional quality of life amongst staff across various healthcare settings (Penz & Duggleby, 2011). Hope may also assist professional caregivers in providing higher quality of care by helping them to foster positive relationships with patients (Duggleby & Wright, 2007).

Various studies have investigated how professional caregivers maintain their hope. Factors found to aid maintenance of hope include; actively engaging with care activities (Simmons & Nelson, 2001), promoting dignity (Clayton, Butow, Arnold & Tattersall, 2005) and sustaining high levels of motivation (Kulig, 2001). Having access to sufficient resources (e.g. adequate staffing levels), encouragement by others, high self-
efficacy (Duggleby, Cooper & Penz, 2009), and feeling that you are making a difference have also been found to be associated with the maintenance of hope. Additionally, having supportive relationships with patients, families and other staff members aided the fostering of hope (Duggleby, 2007). Some professional caregivers report that hope is not realistic in situations where death is looming (Gelling, Fitzgerald & Blight, 2002); this finding may have relevance for dementia care.

**Hope and Dementia**

Hope is an emerging construct in relation to our understanding of living well with dementia. Wolverson, Clarke and Moniz-Cook (2010) sought to explore the personal meaning of hope for people living with early-stage dementia, and the potential facilitators and barriers of hope. Hope was conceptualised as “a generalised motivational force, linked with a sense of determination and agency, which aids an individual to live well, rather than particularised and goal-focussed” (p. 453-458).

Whilst limited to date, research has also investigated the role of hope for family carers of people living with dementia at home and this has relevance for professional caregivers. In a qualitative study conducted by Duggleby, Williams, Wright and Bollinger (2009), participants expressed a fear of hope fading, which was dealt with by finding positives and coming to terms with the caregiving role. Findings suggest hope is a resource that helps family caregivers deal with the challenges of caregiving. Additionally, hope has been connected to lower levels of stress (Irvin & Acton, 1997) and increased quality of life (Duggleby, Swindle, Peacock & Ghosh, 2011). Although caregiving can be a negative experience, these findings are important in a literature base that has typically emphasised stress. Additionally, the research has implications for
understanding the experiences of professional caregivers but equivalent qualitative research has not yet been conducted.

Literature indicates that hope is associated with positive aspects of caregiving in residential dementia care settings. Mullan and Sullivan (2016) sought to clarify the importance of a range of professional caregiver factors associated with having a sense of competence. Hopeful attitudes, in addition to person-centred attitudes towards dementia were found to be significant predictors of a sense of competence. Hopeful attitudes are also related to lower stress levels and job satisfaction (Zimmerman et al., 2005; Moyle, Griffiths & Venturato, 2011). These factors are significant when considering that the caregiver-resident relationship is a determining feature of high quality of care (Bowers, Esmond & Jacobson, 2000). Spector and Orrell (2006) found a significant correlation between resident-assessed quality of life and increased hope in professional caregivers. Although this study does not expand on the nature of hope for care staff or the direction of causality between these factors (i.e. whether, as might be predicted, it is hope that results in improved quality of life), its findings have significant implications for improving quality of life for people living with dementia.

**Rationale and Aims**

Current Positive Psychology (PP) perspectives recognise negative and positive experiences can co-exist and interact as people find ways to overcome challenges and flourish (Wong, 2011; Lomas and Ivtzan, 2015). Hope is associated with well-being but is also often rooted in situations involving adversity and uncertainty. Whilst professional caregiving can offer high levels of job satisfaction, this role is often considered to be highly demanding and underpaid, which can result in high rates of staff turnover (The All-Party Parliamentary Group on Dementia, 2009). These factors are
likely to influence care provided to residents living with dementia and therefore resident outcomes (Bonner, Castle, Men & Handler, 2009; Coogle, Parham, Jablonski & Rachel, 2007).

Existing research indicates the potential value of hope in dementia care and also highlights that non-dementia care staff have an active role in the maintenance of hope (e.g. Penz & Duggleby, 2011), yet little is known about how professional dementia caregivers might experience and sustain hope. This study aimed to address this literature gap and had the following aims:

▪ To understand the meaning and experience of hope for professional caregivers supporting people living with dementia in residential care settings.

▪ To understand how professional caregivers supporting people living with dementia maintain hope in the face of barriers and challenges.

▪ To build a theory that can explain how dementia care staff foster and sustain hope.

Specific research questions in this study were:

▪ How do professional caregivers foster, sustain and experience hope whilst supporting people living with dementia?

▪ What are the facilitators/barriers of hope for professional caregivers supporting people living with dementia?

▪ Does experience of hope facilitate the quality of care provided by dementia care staff?
Method

Design
A constructivist Grounded Theory (GT) approach (Charmaz, 2006) was taken to gather and analyse data yielded via a focus group and subsequent individual interviews. Constructivist GT was utilised due to the limited knowledge base regarding the concept of hope from the perspective of professional dementia caregivers, the potential for hope to have an impact on professional and care-recipient quality of life, and the complex, subjective and dynamic nature of hope. A constructivist GT approach aims to develop a theoretical understanding of a phenomenon, whilst considering the social context in which the research is being conducted (Charmaz, 2006). Charmaz (2006) highlights the value of multiple data sources in constructivist GT in order to yield rich data. Consequently, a focus group of six participants was utilised to inform the direction of the interview schedule for the subsequent nine individual interviews. To help contextualise the qualitative data, demographic data were also collected (see Appendix F).

Participants
Within GT approaches there are no commonly agreed sample sizes (Guest, Bunce & Johnson, 2006). They aim to obtain intentionally heterogeneous samples to increase potential for generalisability if common themes emerge (Robinson, 2014). As suggested by Charmaz (2006) two stages of sampling were used in this study: initial and theoretical sampling.

For initial sampling, inclusion criteria were: professional caregivers supporting and having daily contact with individuals living with dementia (caregivers, healthcare
assistants, activities coordinators etc.). Exclusion criteria were: professional caregivers working in a care home with a poor Care Quality Commission (CQC; England) rating as this could adversely affect staff experiences and confound findings; lack of sufficient fluency in English to take part in the interview; and reluctance to participate in the research. No restriction was placed in relation to length of time working in caregiving as there is no current rationale to base this upon.

Theoretical sampling was subsequently utilised to explore categories emerging from initial coding of data (see below). Emergent thematic categories were used to develop and adapt semi-structured interviews (see Appendix G), and to purposively seek participants with different characteristics; for example, caregivers with varying lengths of experience.

In total, 24 people were approached and 13 people participated in the research. Declining to partake in the study was largely a result of lack of confidence to share one’s views. Six people contributed to the focus group and two people from the group also gave individual interviews at their request. A further seven people participated in individual interviews, resulting in nine individual interviews. 12 people were recruited from one care home, and one from a second care home. The mean age of participants was 35.7, with a range from 21 to 51. Table 4 outlines participant demographics, pseudonyms are used to preserve anonymity (see Appendix H for further information).
### Table 4. A summary of participant demographics

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<td>Yes</td>
</tr>
<tr>
<td>Amanda</td>
<td>Female</td>
<td>&gt;9 years</td>
<td></td>
<td>No</td>
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</table>

**Data Collection**

The Faculty of Health and Social Care Research Ethics Committee within the University of Hull reviewed the study and gave ethical approval (see Appendix I). To begin data collection, five care homes in the North of England were approached to identify a focus group site.
The first positive response came from a ‘not for profit’ organisation specialising in dementia care, with a maximum capacity of 72 residents. Once the care home manager agreed to host a focus group, the researcher attended a staff handover meeting attended by 18 staff at the beginning or end of their shift. The researcher described the process of participation and distributed expression of interest sheets (see Appendix J). Eight individuals were willing to participate and the researcher liaised with the manager to identify a suitable time (using the shift rota). Six individuals were able attend the identified time, and two individuals who were unable to attend were offered individual interviews which they accepted.

For the focus group, a semi-structured interview schedule was created based upon a pilot focus group conducted with healthcare professionals at a memory clinic, key literature and the research questions (see Appendix G) with the aim of enabling participants to interact and express themselves (Stewart, Shamdasani & Rook, 2007). Questions focused on the experience of hope, facilitators/barriers of hope and the role of hope in caregiving. The focus group participant information sheet (see Appendix K) was distributed and individual consent (see Appendix L) sought before the focus group began.

To clarify gaps in emerging theory (Charmaz, 2006), data derived from the focus group informed the development of a semi-structured interview schedule for individual interviews (see Appendix G). For example, themes relating to healthcare governance and length of experience arose during the focus group; questions relating to such themes were therefore added for individual interviews. At each interview, the participant information sheet (see Appendix M) was given and individual consent (see Appendix N) obtained. Following each individual interview, any additional pertinent themes were
used to adapt the interview schedule (see Appendix G) in order to explore these themes further (Charmaz, 2006).

In order to rule out the possibility of findings being restricted to a specific work setting, one participant was sought from a different care home. The second positive response was received from a care home operated by a separate independent care provider specialising in dementia care with a maximum capacity of 58 residents. Permission from the manager was gained, who then liaised with six staff members; one individual left their details on an expression of interest form, and was contacted to arrange an interview.

The focus group and individual interviews were held in the professional caregiver’s place of work, and were digitally recorded. A debrief took place after the focus group and interviews, and a ‘sources of support’ information sheet was provided to each participant. The focus group lasted for 35 minutes and the individual interviews lasted between 27 and 55 minutes (mean= 50 minutes).

**Data Analysis**

Data from the focus group and individual interviews were transcribed and analysed using Constructivist GT (Charmaz, 2006). In accordance with guidance provided by Charmaz (2006), data aggregation and coding involved the following process (see Appendix O for a worked example) to ensure the emergent theory was grounded in the data itself:

- The first stage of analysis was ‘initial coding’ whereby data was coded line by line, simply and precisely.
• The second stage involved ‘focused coding’ whereby categories were created by collapsing and refining the most significant and frequent initial codes.

• The third stage involved ‘theoretical coding’; focused codes were considered in order to make sense of how they related to each other as hypotheses, and how they could be integrated into a theory.

Preliminary analytic notes (memos) were also formed at each level of coding, in order to reflect upon ideas for theoretical coding. In an iterative process data across interviews was evaluated, and compared with different levels of codes to aid the development of the interview schedule, categories and emergent theory. Comparative data may lead to hidden properties of a category (Charmaz, 2006), and consequently the researcher attempted to achieve theoretical saturation. This was undertaken by adjusting the interview schedule and recruiting individuals with different characteristics; for example, individuals with differing levels of professional experience. Consequently, analysis ran in conjunction with data collection to aid identification of gaps in the developing theory. This process is known as constant comparative analysis and is a central feature of GT (Glaser & Strauss, 1967). Theoretical saturation occurs when further collection of data sheds no further light on the research (Charmaz, 2006); participants in this study were approached for interviews until this was attained in respect to the research questions.

The epistemological assumption behind constructivist GT is a constructivist stance, and is relativist; an assumption that there is not an objective truth to be uncovered, rather that truth is a social reality (Guba & Lincoln, 1994) co-created between participants and researcher (Charmaz, 2006). See Appendix P for a full epistemological statement. Therefore, acknowledgement of researcher reflexivity was necessary i.e. the ability to reflect upon research experience and interpretations in order to bring the self into the
process, to allow the reader to consider how and to what extent the researcher influenced the process (Charmaz, 2006). A reflective diary was kept throughout to contemplate these issues. The researcher had previously worked in care homes; witnessing and experiencing attachment with care-recipients, and feeling a sense of role satisfaction whilst in the context of resource difficulties. The researcher was also aware of recent media coverage of poor care and the potential consequences of this for staff. These experiences and thoughts will have influenced interviews and analysis, and is therefore important to consider.

**Results**

Three types of factors comprised an emergent theory of hope amongst dementia care staff; contextual factors, relational factors and individual factors. Contextual factors were aspects of the wider system perceived as external threats or facilitators of hope, relational factors were aspects associated with relationships between professional caregivers and with care-recipients, and individual factors were related to individual caregiver characteristics and attitudes that had a relationship with their sense of hope. These three factors encapsulate nine sub-categories which are either uni-directional or bi-directional with respect to their relationship with carer hope. Uni-directional factors are those which facilitated or hindered hope, and bi-directional factors are those which maintained and were influenced by hope. Each overarching category is described below with illustrative quotes from interviews. Consequently, a model is presented to describe the emergent theory and to demonstrate the dynamic balance between different factors.
**Contextual Factors**

Participants identified several aspects of the caregiving context that constituted potential external threats to hope. These aspects could both hinder and maintain hope.

Media and ‘outsider’ perceptions were consistently seen as aspects of the caregiving context that have the potential to hinder a personal sense of hope. This category includes the negative portrayal of caregiving in the media, particularly with respect to a recent focus on poor care within care homes. Negative perceptions held by those who do not work in care were seen to be largely influenced by the media:

> It’s like now I can’t go into a room without thinking there’s a camera there. Not that I would do anything different but it just makes me paranoid, feeling like someone is watching me all the time. Sometimes I will get all kerfuffled and then I’ll stop and be like what am I doing, calm down it’s probably alright, but you’ve always got that niggle in your ear. It’s horrible, and that’s like media, and you can’t feel hopeful through it at all. There’s no hope when you’re being portrayed like that. (Eleanor)

Some aspects of healthcare governance were also seen as an aspect which could threaten hope. Participants were mostly worried by the consequences of receiving a negative report by an external regulator of care quality (in this case the CQC in England), and the responsibility they might feel for this:

> Many years ago, I remember we got a really bad report. We was [sic] taken through to the dining rooms, probably about 9, 10 years ago, and I can still see it to this day. We was [sic] told you know, we was [sic] abusing people, because people weren’t getting their drink, people weren’t getting this or getting that.
And I literally, physically broke down crying. Obviously, nothing was intentional, no one was saying “you’re not having this” – but things are changing through training and everything, and people weren’t – but we’re a lot more better now. I absolutely broke down crying, I went home and I felt horrified. If that was to happen, that would stop me feeling hopeful, if we were to get bad press or people was to think we weren’t doing our jobs to the best of our ability. (Amanda)

For one participant, hoping for medical advances in dementia arose as a form of particularised hoping but this was identified as a false hope due to the ongoing absence of a cure. Paradoxically, this then gave rise to a sense of hopelessness. This is important in the context of caregiving for people who have an incurable illness; a possible factor which could hinder hope for staff:

I’m hopeful that they will one day find a cure, and everyone will be cured of it, and you can just take a tablet and that will be it, you no longer have dementia and you’ll never get it again, but then I also think will medicine ever advance that much that that would be able to happen, you know what I mean? (Aimee)

Perceived aspects of the care environment itself were important facilitators of hope amongst participants. Having access to adequate resources and investment in the physical building were factors that promoted hope and also as sense of pride in staff:

When one of the top managers came from [care group], he said we was [sic] – the report he gave was that we were excellent, so we was [sic] allowed extra money to improve the home. Obviously everywhere you have a budget, but we was [sic] allowed extra money for improvements, because we were doing so
well, because our rooms are full. Obviously if you’ve got full rooms, you’ve got money coming in. So, that makes me hopeful, like things looking a bit nicer.

(Amanda)

Relational Factors

Throughout interviews participants discussed the importance of hope with respect to relationships with both residents and other professional caregivers. These factors had a direct influence on hope, but were also potentially affected by levels of hope held (i.e. bi-directional).

Seeing residents as people and part of their own family frequently emerged as significant aspects of caregiving that were linked with experiencing hope. This had the potential to hinder hope, for example feeling as though one has ‘let a resident down’. However, relating to residents in this way the potential to facilitate hope, by aiding participants to see positives in their work due to a strong sense of attachment to residents. Some participants also commented on needing hope in order to be able to optimise caregiving and see residents as family. Interestingly some participants commented upon the significance of feeling love for residents as opposed to hopefulness:

I think that’s one of the main things that keeps you in the role, it’s the love you have for the residents. I can’t imagine not seeing them every day, I really can’t.

When I’ve had 5 days off I miss them, they’re like an extended family. (Aimee)

Being part of a functioning team (described as getting along well and having similar goals), frequently emerged as a vital element of hopefulness and effective caregiving. Most participants commented upon how one individual’s hopefulness could have a
powerful ‘knock-on effect’ on the rest of the team, resulting in an ‘easier shift’ and increased hopefulness amongst the team. However, if an individual began their shift with a more hopeless attitude, this had a similar effect. Particularised hoping emerged for those who wanted to remain in their current team:

If you’re all hopeful together and you all support each other, because it can be a demanding job, and an upsetting job, we get very close to these residents. I think if you’re glued together and all working for the same thing, and you’re all there to support each other, it does keep you hopeful. (Jenny)

I’m on a team now and I love it, we all get on so well, we’re like a little family – dysfunctional! (Eleanor)

Meeting resident needs emerged as an important factor for participants. This had the potential to facilitate hope, for example when participants observed the positive effects of caregiving, particularly when psychological needs, beyond physical care needs, were being met. Hopefulness also had the capacity to facilitate this as a way of motivating participants to meet psychological needs of care recipients:

They have dementia, it’s not – they’ve still got a life, they’re still a person, they’re still an individual with all their hopes and dreams, and their wishes for the future. (Jenny)

I don’t think [meeting needs] gives me hope, I think it makes me feel like I’ve achieved something. Erm, I mean I’m always hopeful that I can meet their needs, but when I do, it makes me feel like I’ve done something right. (Aimee)
Individual Factors

Particular characteristics and held attitudes also emerged as significant factors linked with hopefulness throughout interviews. This category comprised both uni-directional and bi-directional factors.

Age and length of experience in care were factors which could affect hopefulness. There were differing views regarding whether older or younger age and limited or extensive experience was associated with higher or lower levels of hope:

I think that, and I don’t want to sound ageist, but I think older people do tend to have less hope than younger people, like I’ve said before. I think coming into a career like caring, I think it’s easier to do when you’re younger because you’ve still got a lot of strength, more open minded, and you learn quicker. (Aimee)

As a young carer, I’ve worked with the older carers, and you know, they’re equally as hopeful, and know the job inside out. (Emma)

Feeling appreciated as a professional was also important for participants and emerged as a uni-directional factor in relation to hope. However, most participants felt they were unappreciated. A sense of achievement following positive feedback and feeling valued could increase hopefulness but feeling unappreciated could hinder hopefulness:

[An interaction in the focus group]

We’re so underappreciated. (Eleanor).

But that’s the care profession in itself, it’s a job that you give give give, and people are always taking, but you don’t get anything back. Mine is that we’re doing a good job and that we go home feeling we’ve done it. If you’re not
feeling appreciated, it will stop you from feeling hopeful about what you’re doing in the work place. (Sarah).

Holding the ‘right’ attitude (described as patience and empathy) was a bi-directional factor, and was seen by participants as both important in effective caregiving and hopefulness. Such attitudes were seen to be a facilitator for hope by some participants, who held a belief that if one was to lose hope, one would no longer have the patience and empathy required for this role. Having the ‘right’ attitude was also seen as a way to maintain hopefulness:

I’ve always said, I know you do get them, but I couldn’t come here and do 40 hours a week, just because I need a pay package. Because if that’s all I come here to do it for, because I needed the money, I’d go find a job elsewhere.

(Bethany)

Emergent Theory

Figure 2 depicts an emergent, grounded model of hope amongst dementia care staff that represents interactions between the factors described above. This model incorporates a dialectical process whereby the maintenance of hope amongst care staff relates to a dynamic balance between different factors. Hope is facilitated by characteristics of the caregiver, including their age, experience and sense of being appreciated; combined with the presence of a positive care environment which can also foster pride. Hope facilitates but is also facilitated by positive person-centered attitudes towards residents along with experiences of positive relationships with other staff members. These factors sustain professional quality of life and good quality care, potentially impacting positively on resident outcomes. However, contextual aspects of caring and the care
environment may hinder hope. These relate to the combined impact of negative media attention, aspects of healthcare regulation viewed by care staff as threatening and blaming, and medical discourses of dementia which place hope solely on an unavailable cure.

![Diagram of factors affecting hope in professional caregivers]

**Figure 2.** An emergent theory of hope in professional caregivers in residential dementia care

**Discussion**

**Overview of Findings**

This study is the first of its kind to examine the meaning and experience of hope amongst professional dementia caregivers and build a theory to explain how hope is sustained in caregiving. Given that hope has been previously linked to quality of care and resident-rated quality of life, these findings have important conceptual and clinical
implications for dementia care. These findings highlight the important role hope plays in sustaining professional quality of life and quality of care. The active experience of caregiver hope is subject to interplay between individual, relational and contextual factors.

**The Experience of Hope in Dementia Caregiving**

The emergent theory of hope derived from the data has similarities with existing accounts of hope but also key divergences. Snyder’s (2002) theory of hope appears to have limited relevance for the experiences of dementia care staff; pathways and agency thinking did not seem to encapsulate the experience of carer hope in this study, although hope may have given caregivers a sense of motivation. However, Dufault and Martocchio’s (1985) conceptualisation of hope, a multi-dimensional motivational force that occurs in a relational context, was particularly relevant to the findings of the study, as well as the notion of generalised and particularised hoping. Overall, participants conveyed generalised hopefulness; whilst also reporting particular aspects they were hoping for, including hope for a cure, and a desire to be part of a well-functioning and familiar team. Therefore, the current study indicates there may be a generalised inner sense of hopefulness amongst caregivers embedded in a relational context in residential dementia care settings, which gives rise to particularised hopes concerning residents, but also aspects of teamwork.

**Facilitators and Barriers to Hope**

A number of the barriers and facilitators to hope that emerged in this study have been reported in previous research exploring hope, but other factors arose which may be unique to dementia care settings. In particular, the importance of relationships between caregivers and residents was highlighted in the findings of this study; being able to see
residents as both people and family members emerged as a particularly salient facilitator of hope. These findings echo the key principles of person-centred care (Kitwood, 1997) and highlight how hope is most likely to occur when care staff feel able to have positive relationships with residents, whilst maintaining person-centred attitudes and meeting resident needs. Duggleby, Cooper and Penz (2009) found receiving encouragement from others facilitated hope amongst healthcare assistants for older adults in various settings; a concept supported by this study regarding the importance of being in a supportive well-functioning team, and feeling appreciated.

Carer age and length of experience emerged as factors potentially linked with hopefulness in the study but there were divergent experiences of this. Elsewhere, Zimmerman et al. (2005) found staff who had been working in dementia care for up to two years had more hopeful attitudes than those who had been working in care for longer. This reflects some experiences in the present study; carers tended to perceive aging as being related to decreased levels of hope.

Healthcare governance, media and outsider perceptions (e.g. inspectors and families) also emerged as significant factors hindering hope within the study. A report prepared for CQC (2013) investigating attitudes of providers of health and social care reflect experiences found within the present study. Negative inspections gave rise to low morale and demotivated staff members. Although such reports can be a catalyst for change, they can also have profound effects on attitudes of staff, and therefore hopefulness. Further, although there is sparse literature around the impact of negative media on the wellbeing of professional caregivers, it has been acknowledged that unremitting negative media reports can be demoralising for staff, particularly when stories of excellent care are often ignored and not reported (Mulley, 2011).
Findings emphasise the importance of good leadership and a supportive environment in instilling a sense of pride and facilitating hope. This is increasingly recognised within both literature and policy (The All-Party Parliamentary Group on Dementia, 2009; Zimmerman et al., 2005). The significance of being part of a well-functioning team fostering mutual emotional support, emerged as a significant factor which could both facilitate and hinder hope. This has not previously been highlighted as an important aspect of hope in care, and is an important new finding requiring consideration due to the potential impact on residents and quality of care provided.

**The Impact of Hope**

Additional key findings relate to how hope can potentially facilitate the quality of care provided by dementia care staff. Factors which emerged as bi-directionally related to hope were particularly relevant to this. Specifically, being able to provide person-centred care, viewing residents as family, and meeting resident needs were made possible by being hopeful, and each in turn increased hopefulness. Previous research conducted by Spector and Orrell (2006) indicates an important positive correlation between resident assessed quality of life and levels of hopefulness in professional caregivers. This study supports their findings and contributes significantly to the literature in regard to aspects which could facilitate professional caregivers’ levels of hopefulness. Further, Arman and Rehnsfeldt (2006) propose the ethical practising of love enables a professional caregiver to act in an authentic manner, which may result in improved quality of care, and is a concept deserving of further investigation.

The results of this study also suggest hope could be a resource for professional caregivers in much the same way as has been found for family caregivers; particularly in respect of maintaining person-centred and compassionate attitudes toward care.
recipients (described as having the ‘right’ attitude by participants in this study). These attitudes are likely linked with the provision of good quality care. However, participants in this study did not express a fear of hopefulness declining, as was found by Duggleby et al. (2009) amongst family caregivers; possibly indicating differences in the experience of hope between family and professional caregivers.

**Implications**

Interventions and training packages targeting both hope facilitating and hope hindering factors could help sustain positive experiences of caregiving amongst dementia care staff; for example, by addressing relationship issues and team working. Professional caregivers may play an active role in maintaining their own hope (Penz & Duggleby, 2011); training and support initiatives or interventions aimed at increasing self-efficacy and team-work could be helpful in fostering hope in dementia care.

Future research could investigate relationships highlighted by the findings of this study and proposed links between contextual, relational and individual factors. As such, the emergent theory presented here should be tested using an adequately powered quantitative design, which utilises relevant quantitative measures of hope known to have robust psychometric properties (e.g. Herth Hope Index; Herth, 1992).

**Limitations**

This study must be considered in relation to its limitations. Firstly, all participants were White British and lived in the North of England. Therefore, the emergent theory cannot be generalised to professional caregivers across different cultures. Secondly, a volunteer bias must be acknowledged; a professional caregiver may be more inclined to volunteer if they are invested in the role and feel more hopeful. Caregivers who lacked hope were
probably unlikely to volunteer in such a study. Thirdly, all but one of the participants were female; although this is generally representative of the workforce, further pertinent information may have emerged with more male participants included.

**Conclusions**

In conclusion, a dynamic interplay of personal, contextual and relational factors act to hinder and facilitate a professional caregiver’s hopefulness whilst supporting people living with dementia. The findings highlight the significant role hope may play in professional quality of life and quality of care provided.
References


Part Three: Appendices
Appendix A: Instructions for contributors to the journal International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, brief reports, "for debate" articles, case reports, letters to the editor, book reviews and guest editorials. Apart from editorials, "for debate" articles and book reviews, which are commissioned, contributions to International Psychogeriatrics are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in-Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2015) is 2.220. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English.

Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. International Psychogeriatrics uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. International Psychogeriatrics has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (www.cambridge.org/core/journals/international-
psychogeriatrics) under the related links icon and the IPA website (http://www.ipa-online.org/).

The editorial team have decided not to publish papers whose sole focus is the validation of translated instruments that have previously been well assessed and validated in English (or another language). These are better placed in a relevant National, rather than an International, journal.

**Submission of manuscripts**

**Note: It is not acceptable to submit to the journal an article that has previously been published or submitted elsewhere. Authors are required to assert that they have not submitted their article elsewhere upon submission to International Psychogeriatrics.**

Manuscripts should be submitted online via our manuscript submission and tracking site, http://mc.manuscriptcentral.com/ipg. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au

To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading ‘Submission of randomized clinical trials’ on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:
1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.

2. That the authors have had full control of all the primary data.

3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. The Editor-in-Chief’s decision to accept, reject or request revision of the paper for publication will be final. The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors’ names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers’ names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in International Psychogeriatrics.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne, RMH Royal Park Campus, 34-54 Poplar Road, Parkville, Victoria 3052, Australia, Tel: +61 3 8387 2326, Fax: +61 3 8387 2667. Most authors can expect to receive an initial decision on the fate of their paper together with referees’ reports within no more than 100 days of
submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

**Submission of papers reporting randomized controlled trials**

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals International Psychogeriatrics has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in International Psychogeriatrics. International Psychogeriatrics, 18, 191-193.

**All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.**

a. A check list and flow chart in accordance with the CONSORT guidelines which can be found at [http://www.consort-statement.org](http://www.consort-statement.org). Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.

b. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.

c. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper’s structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in International Psychogeriatrics. Trials that began enrolment prior to 30 November 2006 must have been registered no later
than that date. Our criteria for a suitable public trial registry are: free to access; searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.

**Organization and style of research articles**

**Title page and corresponding author:** Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Each author must select only ONE country as their location. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author’s email address, telephone number, fax number and postal address must be clearly stated.

**Abstract:** Abstracts for original research and reviews should be structured and incorporate 4 sub-headings: background, method(s), results, conclusion(s). Abstracts for protocol only papers should omit the third sub-heading (Results). Abstracts for brief reports and case reports should have no sub-headings. Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length. Abstracts for brief reports should not exceed 200 words.

**Key words:** Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

**Running title:** This should contain no more than 50 characters including spaces.

**Introduction:** Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

**Methods:** Materials and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be
justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

Further advice about statistics and International Psychogeriatrics can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. International Psychogeriatrics, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in International Psychogeriatrics for the year 2003. International Psychogeriatrics 16, 389-396. Both of these are available at the International Psychogeriatrics website by following the link to Statistical Advice for intending contributors. This is also located under the related links icon at the journal homepage (www.cambridge.org/core/journals/international-psychogeriatrics).

**Results:** This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, η², Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ²).

**Discussion:** Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological weaknesses of the study should be outlined, including limitations
imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

**Conflict of interest declaration:** This section must be completed. This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word "none" underneath it. For full details see below.

**Description of authors’ roles:** This section must be completed if the paper has 2 or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

**Acknowledgements:** Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

**References:** For original research no more than 30 articles that have been published or are in press should be cited, and for brief reports no more than 15 references. If authors believe that more than 30 references are essential to an original research article this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. International Psychogeriatrics uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term "et al." should be employed, i.e., (Smith et al., 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith et al., 1999). At the end of each paper, all cited references should be listed.
alphabetically in 5 the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.


Where an article or book chapter has more than six authors only the first author’s name should be given followed by the words "et al.".

For further examples of reference style see papers in recent issues of International Psychogeriatrics.

Figures/Tables: The manuscript should contain no more than five figures or tables (no more than three figures or tables for brief reports). The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in come issues but authors wishing to publish figures requiring colour to communicate the data may be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Supplementary material: More detail about the submission of supplementary material is available below – see "Supplementary Material for online only publication" and "Instructions for contributors – Supplementary Material" in subsequent pages of this document.
Word limits: At present International Psychogeriatrics does not have a fixed word limit for articles, other than for brief reports for which the word limit is 1500. Because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Brief Reports

This category allows for articles that are shorter than original research but have the same style and may be used to report new and innovative research and/or significant (hot topics). Unlike letters to the editor, brief reports are peer reviewed. They should be of 1500 words or less and include no more than three figures or tables, no more than 15 references, and have an unstructured abstract of no more than 200 words. They may contain supplementary material which is published online only.

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of International Psychogeriatrics to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

"For Debate" Articles

From time to time International Psychogeriatrics will publish "For debate" articles on topics of a controversial nature. "For debate" articles will be commissioned by the editor, but readers are welcome to suggest possible topics for debate by contacting the editor at ipaj-ed@unimelb.edu.au. To view recently published debates see journal issues 19(6), 20(2), and 21(2).
Case Reports

Case reports will be accepted for review and considered for publication. They should be of 1200 words or less and should have no more than 10 references. An unstructured abstract of 100 words or less is required. When submitting case reports authors must enclose a letter of consent to publication from each of the patient(s) described or, if the patient(s) is/are deceased or not competent to consent the authors must indicate that they have obtained such consent from the patient's legal guardian(s). These letters will be kept confidential.

Study protocol articles

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http://journals.cambridge.org/ipg. This renders such supplementary material accessible without clogging the journal with materials that will be of interest to only a small minority of readers. If submitting such supplementary material please follow the instructions below. If referring to supplementary material in a paper the following form of words should be used "see table S1/figure S1/appendix A1 published as supplementary material online attached to the electronic version of this paper at http://journals.cambridge.org/ipg".

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A description of any sponsor’s role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by Bigpharma which directly competes with another drug made by Megadrug a declaration might say "Jane Smith has received research support and speaker’s honoraria from Bigpharma and has received financial assistance from Megadrug to enable her attend conferences."
Appendix B: Data Extraction Tool

**Data Extraction Form**

Full reference

Search terms used to find the study & database

Location of study

Background & Objectives

Participants – number and demographic information

Method – including measures

Results

Other relevant information

Excluded/included – rationale
# Appendix C: Adapted Quality Assessment Tool

**Study identification**: Include full citation details

**Assessed by:**

### Section 1: Theoretical approach

<table>
<thead>
<tr>
<th>1. Is the study clear in what it seeks to do?</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is the purpose of the study discussed – aims, objectives, research questions?</td>
<td>++</td>
</tr>
<tr>
<td>• Is there adequate/appropriate reference to the literature?</td>
<td>+</td>
</tr>
<tr>
<td>• Are underpinning values, assumptions and theory discussed?</td>
<td>−</td>
</tr>
</tbody>
</table>

### Section 2: Study design

<table>
<thead>
<tr>
<th>2. How defensible/rigorous is the research design?</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is the design appropriate to the research question?</td>
<td>++</td>
</tr>
<tr>
<td>• Are there clear accounts of rational for sampling, data collection and data analysis used?</td>
<td>+</td>
</tr>
</tbody>
</table>

### Section 3: Population

<table>
<thead>
<tr>
<th>3. Is the source population or source area well described?</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described?</td>
<td>++</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Is the eligible population or area representative of the source population or area?</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>•</td>
<td>++</td>
</tr>
</tbody>
</table>

97
<table>
<thead>
<tr>
<th>Section 4: Outcomes</th>
<th>6. <strong>Were the outcome measures and procedures reliable?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Were</strong> outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking −)?</td>
</tr>
<tr>
<td></td>
<td><strong>How reliable</strong> were outcome measures (e.g. inter- or intra-rater reliability scores)?</td>
</tr>
<tr>
<td></td>
<td><strong>Was</strong> there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 5: Analyses</th>
<th>7. <strong>Is the data analysis sufficiently rigorous?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Is</strong> the procedure explicit i.e. is it clear how the data was analysed to arrive at the outcome?</td>
</tr>
<tr>
<td></td>
<td><strong>How systematic</strong> is the analysis, is the procedure reliable?</td>
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<tr>
<td></td>
<td></td>
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<tr>
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<td>---</td>
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</tbody>
</table>
| 8. **Was the precision of association given or calculable? Is association meaningful?** | ++
| • Were confidence intervals or p values for effect estimates given or possible to calculate? | +
| • Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered? | NR
| Comments: | NA

| 9. **Are findings convincing?** | ++
| • Are the findings clearly presented? | +
| • Is the reporting clear and coherent? | −

| 10. **Are the findings relevant to the aims of the study?** | ++
| | +
| | −

| 11. **Conclusions** | ++
| • How clear are the links between data, interpretation and conclusions? | +
| • Are the conclusions plausible and coherent? | −
| • Does this enhance understanding of the topic? | −

**Section 6: Summary**

| 12. **Are the findings generalisable to the source population (i.e. externally valid)?** | ++
| • Are there sufficient details given about the study to determine if the findings are generalisable to the source population? | +
| • Consider: participants, interventions and comparisons, outcomes, resource and policy implications. | −
| Comments: | Comments:

| 13. **As far as can be ascertained from the paper, how well was the study conducted?** | ++
| Comments: | Comments: |
Adapted from:


Appendix D: Summary table of quality assessment for included studies

<table>
<thead>
<tr>
<th>Article</th>
<th>Checklist Item Score</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Brodaty et al. (2003)</td>
<td>2 2 2 2 1 1 2 2 2 1</td>
<td>81</td>
</tr>
<tr>
<td>Drebing et al. (2002)</td>
<td>2 2 1 2 2 1 2 2 2 1</td>
<td>85</td>
</tr>
<tr>
<td>Duffy et al. (2009)</td>
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<td>88</td>
</tr>
<tr>
<td>Edvardsson et al. (2009)</td>
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<td>73</td>
</tr>
<tr>
<td>Hughes et al. (2008)</td>
<td>2 2 2 2 2 0 2 2 2 2</td>
<td>85</td>
</tr>
<tr>
<td>Jenkins and Allen (1998)</td>
<td>2 2 2 1 1 1 1 1 2 2</td>
<td>69</td>
</tr>
<tr>
<td>Kimura et al. (2011)</td>
<td>2 2 2 1 1 1 2 2 2 1</td>
<td>85</td>
</tr>
<tr>
<td>Lee et al. (2013)</td>
<td>2 2 2 2 1 0 2 2 2 2</td>
<td>85</td>
</tr>
<tr>
<td>Study</td>
<td>1</td>
<td>2</td>
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<td>-------------------------------</td>
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</tr>
<tr>
<td>Moyle et al. (2011)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Mullan and Sullivan (2016)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Schmidt et al. (2014)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Spector and Orrell (2006)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Testad et al. (2010)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Zimmerman et al. (2005)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total (%)</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>
Appendix E: Manuscript preparation for authors of the journal Aging & Mental Health

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

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  o Word limits
  o Style guidelines
  o Formatting and templates
  o References
  o Checklist
• Using third-party material in your paper
• Disclosure statement
• Clinical Trials Registry
• Complying with ethics of experimentation
  o Consent
  o Health and safety
• Submitting your paper
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• Copyright options
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• Open access
• My Authored Works
• Article reprints

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*Aging & Mental Health* is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal’s Aims & Scope for information about its focus and peer-review policy.

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All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

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Your paper should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
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Please include a word count for your paper.
A typical manuscript for this journal should be no more than 5000 words; this limit does not include tables; references; this limit includes figure captions; footnotes; endnotes. A typical short report for this journal should be no more than 2000 words; this limit does not include tables; references; this limit includes figure captions; footnotes; endnotes.

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Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.
Please use any spelling style consistently throughout your manuscript.
Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

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Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting templates.

A LaTeX template is available for this journal.

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact authortemplate@tandf.co.uk

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Checklist: what to include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. Please include all authors’ full names, affiliations, postal addresses, telephone numbers and email addresses on the title page. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors’ affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. A structured **abstract** of no more than 250 words. A structured abstract should cover (in the following order): : Objectives, Method, Results, and Conclusion. Read tips on writing your abstract.

3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

4. **3 to 5 keywords.** Read making your article more discoverable, including information on choosing a title and search engine optimization.

5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

   *For single agency grants:* This work was supported by the[Funding Agency] under Grant [number xxxx].

   *For multiple agency grants:* This work was supported by the [funding Agency 1]; under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx].

6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
7. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper’s study area accurately in JournalMap’s geographic literature database and make your article more discoverable to others.

8. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

9. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be saved as TIFF, PostScript or EPS files. More information on how to prepare artwork.

10. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

11. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

12. **Units.** Please use SI units (non-italicized).

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number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

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Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors’ Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

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**Queries**

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*Updated September 2016*
Appendix F: Participant Demographic Form

INFORMATION ABOUT YOU
Please answer the following questions:

Please tick ✓

1. What is your age in years?


2. Gender – do you identify as?

Male ☐ Female ☐ Other (please specify below if you wish) ☐

3. Ethnic group – which describes you best?

☐ White British ☐ Other Asian background
☐ Other White background ☐ Black Caribbean and White
☐ Black British ☐ Black African and White
☐ Black African ☐ Asian and White
☐ Black Caribbean ☐ Other Dual Heritage
☐ Other Black background ☐ Chinese
☐ Indian ☐ Traveller
☐ Pakistani ☐ Bangladeshi
☐ Other Ethnic Group ☐ Prefer not to say

4. Relationship status (please tick any that apply):

☐ single
☐ engaged
☐ married
☐ civil partnership
☐ divorced
☐ separated
☐ cohabiting
☐ widowed
5. Length of time in caring profession:

- [ ] Less than 6 months
- [ ] 6 months-1 year
- [ ] 1-3 years
- [ ] 4-6 years
- [ ] 7-9 years
- [ ] More than 9 years

6. Type of home:

- [ ] Nursing
- [ ] Residential
- [ ] Specialist dementia care
- [ ] Other

7. Hours of contact with residents a week (approx.):

.................................................................

8. Any personal experience of dementia (family members or friends living with dementia):

- [ ] Yes
- [ ] No

9. Highest level of education:

- [ ] no formal qualifications
- [ ] age 16 (e.g. GCSEs)
- [ ] age 16-18 (e.g. AS/A-levels)
- [ ] other please state:
Appendix G: Interview Schedule

The following questions were used as a guide for the focus group, based on Penz and Duggleby (2011). The following questions were then adapted from the data found in the focus group, to form the schedule for one-to-one interviews, to help clarify and define gaps in any emergent theory.

Original transcript (language adapted for group or individual use)

Questions added for 10/12/16 onwards

Questions added for 20/12/16 onwards

Your role

How did you get into caregiving?

What are the best/worst bits of this job?

Meaning and experience of hope

When was the last time you felt hopeful?

Does hope play a part in your role as a caregiver? If so, how?

Facilitators/barriers of hope

Is there anything that can help you remain hopeful?

What are the aspects of this role that may stop you from being hopeful?

Do you believe there is link between the length of time in the role and hope?

Do you think age can affect how hopeful someone is?
Can you tell me how meeting a resident’s needs may affect your sense of hope? How does providing the psychological element of care affect your sense of hope?

Others have talked about feeling like part of a team/group; how could being part of a group give you hope? Would you say it’s the other way around?

Do you think external things like media and CQC are a threat to hope? How do you sustain hope in the face of these things?

If you have stuff going on at home, how does that effect how hopeful you are here?

*Does your personal experience of dementia affect how hopeful you are?

Do people at home understand how challenging the role can be? Can that effect your hope here?

**Sustaining caregiving**

Do you think hope influences your caregiving?

What role does hope have in your role?

Do you believe hope can keep people in this job? If you weren’t hopeful, could you keep doing this job?
## Appendix H: Participant Demographic Table

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Relationship Status</th>
<th>Time in Caring</th>
<th>Type of Home</th>
<th>Hours of Contact</th>
<th>Personal Experience of Dementia</th>
<th>Level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>Female</td>
<td>White</td>
<td>Married</td>
<td>&gt;9 years</td>
<td>Residential</td>
<td>40</td>
<td>Yes</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Katie</td>
<td>Female</td>
<td>White</td>
<td>Married</td>
<td>4-6 years</td>
<td>Residential</td>
<td>40</td>
<td>No</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Danielle</td>
<td>Female</td>
<td>White</td>
<td>Married</td>
<td>&gt;9 years</td>
<td>Residential</td>
<td>40</td>
<td>No</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Eleanor</td>
<td>Female</td>
<td>White</td>
<td>Single</td>
<td>4-6 years</td>
<td>Residential</td>
<td>37</td>
<td>No</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Irene</td>
<td>Female</td>
<td>White</td>
<td>Divorced</td>
<td>4-6 years</td>
<td>Residential</td>
<td>37</td>
<td>Yes</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Lorna</td>
<td>Female</td>
<td>White</td>
<td>Single</td>
<td>½-1 year</td>
<td>Residential</td>
<td>37</td>
<td>No</td>
<td>Diploma level 2</td>
</tr>
<tr>
<td>Jenny</td>
<td>Female</td>
<td>White</td>
<td>Cohabiting</td>
<td>&gt;9 years</td>
<td>Residential</td>
<td>40</td>
<td>Yes</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Race</td>
<td>Marital Status</td>
<td>Duration</td>
<td>Location</td>
<td>Age</td>
<td>Employment Status</td>
<td>NVQ Level</td>
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<tr>
<td>--------</td>
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</tr>
<tr>
<td>Aimee</td>
<td>Female</td>
<td>White</td>
<td>Engaged</td>
<td>1-3 years</td>
<td>Residential</td>
<td>30</td>
<td>Yes</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Emma</td>
<td>Female</td>
<td>White</td>
<td>Engaged</td>
<td>½-1 year</td>
<td>Residential</td>
<td>37.5</td>
<td>Yes</td>
<td>Degree</td>
</tr>
<tr>
<td>Edward</td>
<td>Male</td>
<td>White</td>
<td>Single</td>
<td>&lt;6 months</td>
<td>Residential</td>
<td>37</td>
<td>No</td>
<td>Diploma level 2</td>
</tr>
<tr>
<td>Bethany</td>
<td>Female</td>
<td>White</td>
<td>Single</td>
<td>4-6 years</td>
<td>Residential</td>
<td>30</td>
<td>Yes</td>
<td>NVQ level 2</td>
</tr>
<tr>
<td>Jackie</td>
<td>Female</td>
<td>White</td>
<td>Single</td>
<td>&gt;9 years</td>
<td>Residential</td>
<td>37</td>
<td>Yes</td>
<td>NVQ level 3</td>
</tr>
<tr>
<td>Amanda</td>
<td>Female</td>
<td>White</td>
<td>Widowed</td>
<td>&gt;9 years</td>
<td>Nursing</td>
<td>36</td>
<td>No</td>
<td>NVQ level 3</td>
</tr>
</tbody>
</table>
Appendix I: Documentation of Ethical Approval

(REMOVED FOR HARD BINDING)
Appendix J: Expression of Interest Form

Hope in Professional Caregivers Supporting Individuals Living with Dementia

If you interested in taking part in the study detailed on the information sheet provided, please leave your contact details on the space below. You will be contacted by the researcher Lucy, to arrange a meeting at a convenient place and time.

Your Name: ........................................................................................................................................

Telephone Number(s): 

........................................................................................................................................

........................................................................................................................................

Are there any times of the day you prefer to be contacted?

........................................................................................................................................

Do you have any further comments?

........................................................................................................................................

........................................................................................................................................

........................................................................................................................................

Signature:

Date:

Thank you for your interest and taking the time to fill out this form.
Title of the study: Hope in Professional Caregivers Supporting Individuals Living with Dementia

We would like to invite you to take part in our research study, which is investigating the experience of hope in professional caregivers supporting older people living with dementia. Prior to deciding if you want to participate, we would like you to understand why this research is being conducted. We would also like you to understand what will happen should you decide to participate. You may wish to chat to other people before you decide whether to take part and the researcher will be happy to answer any questions you might have after reading this.

What is the purpose of the study?

Caring for people living with dementia is a demanding and highly skilled job. Yet we know very little about the experience of staff caregivers and the skills that it takes to do this job. We are interested in hearing about the experiences of staff caregivers and in particular about the role hope might play in your working life. We would like to know more about what keeps people hopeful at work, what might cause them to lose hope and what that can feel like.

Why have I been invited?

This information is given to staff working in this care home who have daily contact with people living with dementia (this includes carers, domestic staff and activities staff). We are looking for around eight people to take part in a focus group. A focus group is where a group of people can share their views about a topic – in this case it will be a relaxed chat about your experience of hope in your role.

Do I have to take part?

No, participation in this study is completely voluntary. If you decide you want to take part in the study, please leave your name on the expression of interest form attached to this sheet. You will then be contacted by the researcher to arrange a suitable time for you and several of your colleagues to take part in a group discussion.

You are free to withdraw from the study up to the point where the results are analysed, and you do not have to give a reason for this. Your decision will not affect your employment within your workplace.

What will happen if I decide to take part?

You will have to answer some short questions about you on a form, for example your age and gender and sign a consent form to say you agree to take part. Then you will have a discussion with up to seven of your colleagues from your care home and with the researcher Lucy which will last around an hour. The researcher Lucy who is a trainee clinical psychologist will be asking the group to talk about their day to day working life and
experiences of hope whilst they are working, and anything that might facilitate/prevent hope. The discussion will be taped. There are no right/wrong answers – we are interested in your experiences.

We are only looking for around eight people to take part in the group chat – if more people are interested in the study they may be offered the chance to take part in a one-to-one interview. If you would prefer to speak to the researcher alone than in a group, please write this on the expression of interest form (attached) or let Lucy know when you speak to her. If more than eight people agree to take part, those people may be asked to participate in the next stage of this study (individual interviews). This stage is similar to the group interview, but will be one-to-one instead. Information on this stage is available should you wish to contact the researcher beforehand.

**What are the possible disadvantages and risks of taking part?**

Participating in this study will require about an hour of your time. Sometimes people can get upset when thinking about hope if they begin to feel hopeless. Should this happen, Lucy will offer any support you need. You can also access help from your GP or Single Point of Access, if needed.

**What are the possible benefits of taking part?**

We cannot say that you will have any direct benefits from taking part in this study. However, it is hoped that sharing information about your experiences of hope will help us to understand more about hope and how staff members may use hope.

**What will happen if I decide I no longer wish to take part?**

You are free to withdraw from the study before the results are analysed without giving a reason. This will not affect your employment in your workplace.

**What if there is a problem?**

If you have any concerns about taking part in the study, you can contact the researcher or their supervisors, who will do their best to answer your questions. These details are at the end of this document.

**Will my taking part in this study be kept confidential?**

Yes, all the personal information you provide will be kept strictly confidential. Although we will be setting ground rules about keeping what is said in the group private, we cannot guarantee your colleagues will adhere to this.

Personal information that could identify you will be blocked out and not used. For those who decide to take part, we will give you a participant number, rather than using your name. After the research is completed, the recordings will be destroyed.

The only time that information cannot be kept confidential is if you disclose something that suggests you or someone else (for example individuals who you provide support for) is/has been at risk of serious harm. Additionally, if any aspects of poor care are disclosed,
confidentiality cannot be kept. If this happens during the interview the researcher would need to share this information to ensure that you and others are safe (such as your managers or safeguarding services).

**What will happen to the results of the study?**

After the study is completed, a written summary of the overall findings will be given to your manager to hand out. The results will be written-up and submitted for a thesis and publication in an academic journal. Some direct quotes from what you say may be used, but your personal details/any identifiable information will not be included in the write-up.

**Who is organising and funding the research?**

This study is being conducted as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant portions of data collected during the study (which are relevant to taking part in this research) may be looked at by the supervisors of this research, responsible individuals from the University of Hull or from regulatory authorities to ensure appropriate guidance was followed by the researcher.

**Who has reviewed the study?**

The study is reviewed a Research Ethics Committee at the University of Hull, which is an independent organisation. The Research Ethics Committee protects the interest of those who take part in the study. They have given the study approval to go ahead.

If you have any further questions, comments, or concerns, please do not hesitate to contact Lucy Bartels. Thank you for taking the time to read this information sheet.

Yours Sincerely,

Lucy Bartels
Trainee Clinical Psychologist

Supervised by,

Dr Emma Wolverson
Clinical Psychologist

Dr Chris Clarke
Clinical Psychologist

**Contact details:**

**Lucy Bartels**
The Department of Psychological Health and Wellbeing
Aire Building
The University of Hull
Cottingham Road
Hull HU6 7RX
Tel: 07468516275
Email: l.bartels@2011.hull.ac.uk

**Dr Emma Wolverson**
The Department of Psychological Health and Wellbeing
Aire Building
The University of Hull
Cottingham Road
Hull HU6 7RX
Appendix L: Participant Consent Form (Focus Group)

CONSENT FORM

Title of Project: Hope in Professional Caregivers Supporting Individuals Living with Dementia (Focus group)

Name of Researcher: Lucy Bartels

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 5/2/16 (Version 1.2) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription, without my employment being affected.

3. I confirm that direct quotes from the focus group may be used in future publications and understand that they will be anonymised.

4. I agree to take part in the focus group and understand that participation in the discussion will be audio taped.

5. I understand that disclosure of any poor caregiving will be reported to relevant management or safeguarding services.

Name __________________________ Date __________________________ Signature __________________________

Name of person taking consent __________________________ Date __________________________ Signature __________________________
Appendix M: Participant Information Sheet (Individual Interview)

Title of the study: Hope in Professional Caregivers Supporting Individuals Living with Dementia

We would like to invite you to partake in our research study which is investigating the experience of hope in professional caregivers supporting older people living with dementia. Prior to deciding if you want to participate, we would like you to fully understand why this research is being conducted. We would also like you to understand what will happen should you decide to participate. You may wish to chat to other people before you decide whether to take part and the researcher will be happy to answer any questions you might have after reading this.

What is the purpose of the study?

Caring for people living with dementia is a demanding and highly skilled job. We know very little about the experience of staff caregivers and skills it takes to do this job. The study is interested in how professional caregivers use hope in their daily working life. We are also looking to understand the potential factors that may facilitate/prevent a caregiver returning to work each day and fostering hope. From this information, we hope to understand more about how staff caregivers use hope.

Why have I been invited?

This information is given to any individual who has daily contact with individuals living with dementia. We are looking for people to take part who work in care homes, who would be willing to have a chat with Lucy, the researcher about their work.

Do I have to take part?

No, participation in this study is completely voluntary. If you decide to take part in the study, please leave your name on the expression of interest form which will be with your manager, or a in a communal area. You will then be contacted by the researcher to arrange a suitable time and place for you to have a chat with the researcher (should you agree to take part).

You are free to withdraw from the study up to the point where the results of your interview are analysed, and you do not have to give a reason for this. Your decision will not affect your employment within your workplace.

What will happen if I decide to take part?

You will have to answer some short questions about you on a form, for example your age and gender, and sign a consent form to say you agree to take part. You will then have a chat with the researcher which will last about an hour. The researcher Lucy who is a trainee clinical psychologist will be asking to you talk about your day to day working life and experiences of hope whilst working, and anything that might facilitate/prevent hope.
The chat will be taped. There are no right/wrong answers – we are interested in your experiences.

**What are the possible disadvantages and risks of taking part?**

Participating in this study will require about an hour of your time. Sometimes people can get upset when thinking about hope if they begin to feel hopeless. This probably won’t happen – but if it does, Lucy will offer any support you need. You can also access help from your GP or Single Point of Access, if needed.

**What are the possible benefits of taking part?**

We cannot say that you will have any direct benefits from taking part in this study. However, it is hoped that sharing information about your experiences of hope will help us to understand more about hope and how staff members may use hope.

**What will happen if I decide I no longer wish to take part?**

You are free to withdraw from the study before the results are analysed without giving a reason. This will not affect your employment in your workplace.

**What if there is a problem?**

If you have any concerns about taking part in the study, you can contact the researcher or their supervisors, who will do their best to answer your questions. These details are at the end of this document.

**Will my taking part in this study be kept confidential?**

Yes, all the personal information you provide will be kept strictly confidential. Any information you give that could be used to identify you will not be used in the research. For those who decide to take part, we will give you a participant number, rather than using your name. After the research is completed, the tape recordings will be destroyed.

The only time that information cannot be kept confidential is if you disclose something that suggests you or someone else (for example individuals who you provide support for) is/has been at risk of serious harm. Additionally, if any aspects of poor care are disclosed, confidentiality cannot be kept. If this happens during the interview the researcher would need to share this information to ensure that you and others are safe (such as management or safeguarding services).

**What will happen to the results of the study?**

After the study is completed, a summary of the overall findings of the study will be given to your manager to hand out. The results will be written-up and submitted for a thesis and publication in an academic journal. Some direct quotes from what you say may be used, but your personal details/any identifiable information will not be included in the write-up.

**Who is organising and funding the research?**
This study is being conducted as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant portions of data collected during the study (which are relevant to taking part in this research) may be looked at by the supervisors of this research, responsible individuals from the University of Hull or from regulatory authorities to ensure appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed a Research Ethics Committee at the University of Hull, which is an independent organisation. The Research Ethics Committee protects the interest of those who take part in the study. They have given the study approval to go ahead.

If you have any further questions, comments, or concerns, please do not hesitate to contact Lucy Bartels. Thank you for taking the time to read this information sheet.

Yours Sincerely,

Lucy Bartels
Trainee Clinical Psychologist

Supervised by,

Dr Emma Wolverson
Clinical Psychologist

Dr Chris Clarke
Clinical Psychologist

Contact details:

Lucy Bartels
The Department of Psychological Health and Wellbeing
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07468516275
Email: l.bartels@2011.hull.ac.uk

Dr Emma Wolverson
The Department of Psychological Health and Wellbeing
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 01482 464170
Email: e.wolverson@hull.ac.uk

Dr Chris Clarke
The Department of Psychological Health and Wellbeing
Aire Building
University of Hull
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Hull
HU6 7RX
Tel: 01482 464106
Email: c.clarke@hull.ac.uk
CONSENT FORM

Title of Project: Hope in Professional Caregivers Supporting Individuals Living with Dementia (Individual interview)

Name of Researcher: Lucy Bartels

1. I confirm that I have read and understand the information sheet dated 5/2/2016 (Version 1.2) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription, without my employment being affected.

3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.

4. I agree to take part in the interview and understand that the interview will be audio taped.

5. I understand that disclosure of any poor caregiving will be reported to relevant management or safeguarding services.

Name __________________________  Date __________________________  Signature __________________________

Name of person taking consent __________________________  Date __________________________  Signature __________________________
## Appendix O: Example of Coding Process

<table>
<thead>
<tr>
<th>Quote</th>
<th>Open coding</th>
<th>Focused coding</th>
<th>Theoretical coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s like now I can’t go into a room without thinking there’s a camera there. Not that I would do anything different but it just makes me paranoid, feeling like someone is watching me all the time. Sometimes I will get all kerfuffled and then I’ll stop and be like what am I doing, calm down its probably alright, but you’ve always got that niggle in your ear. It’s horrible, and that’s like media, and you can’t feel hopeful through it at all. There’s no hope when you’re being portrayed like that. (Eleanor)</td>
<td>Not being able to enter a resident’s room without being paranoid</td>
<td>Media and outsider perceptions</td>
<td>Contextual factors</td>
</tr>
<tr>
<td>The minute they walk through the door, everybody is on high alert. We try so hard to make it a warm, friendly atmosphere, and a family, and sometimes when they come in and find little bits and bobs and all the rest of it, it’s so hard. It can be a bit demoralising, and you think “oh… they’re here”, and you do feel nervous, and frightened you’re going to say the wrong thing. (Jenny)</td>
<td>Being on high alert when CQC arrive Efforts to make a friendly atmosphere CQC reports on minor aspects and can be demoralising Feeling nervous and being frightened about saying the wrong thing</td>
<td>Healthcare governance</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Yeah, I mean I hope that every single resident that we’ve got is going to miraculously get better, even though I know it’s very very unlikely that would happen. Like I know they’re working on all kinds of like drugs and treatments for dementia, but I know it’s very unlikely we would see a cure in our lifetime, like especially in their lifetime. So, I mean I am hopeful that one day they’ll find</td>
<td>Hoping residents will get better Hope despite knowing improvements are unlikely to happen Knowledge of research into treatment Considering when treatments will come available</td>
<td>Medical advances</td>
<td></td>
</tr>
<tr>
<td>a cure for it, but then I’m also quite kind of sceptical, thinking well you know – you know what I mean? (Aimee)</td>
<td>Being sceptical about a cure becoming available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recently we was allowed to have some money to have work done, because when one of the top managers came from [care group], he said we was, the report he gave was that we were excellent, so we was allowed extra money to improve the home. Obviously everywhere you have a budget, but we was allowed extra money for improvements, because we were doing so well, because our rooms are well. Obviously if you’ve got full rooms, you’ve got money coming in. So, that makes me hopeful, like things looking a bit nicer. (Amanda)</td>
<td>Receiving permission for improvements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visit from management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving a positive report leading to additional resources for improvements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A sense of pride due to achievement of doing well as a business</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling hopeful when the care environment has improved</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I think, I don’t really think it’s hope that keeps people in the role, I think it’s more like, the actual love that you have for the residents.</td>
<td>Hope doesn’t keep people in the job, rather the love a carer feels for residents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeing residents as Relational factors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because I mean, I go home at night and I’m laid in bed wondering how so and so’s doing, I wonder if they’re in bed or walking about or if they need a drink, if they’re getting looked after properly. (Aimee)</td>
<td>Thinking about residents at home; wondering about their well-being</td>
<td>people and family</td>
<td></td>
</tr>
<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>I’m on a team now and I love it, we all get on so well, we’re like a little family – dysfunctional! It’s great because we all know where we’re going, we don’t even need to tell each other what we’re doing because we just know what’s happening … But that makes you feel hopeful, it’s like you know what, we just get on and plod along. Just throw anything at us, we’ll take it and probably winge, but because we’re a unit, we know we’ll be fine, let it go over our heads. (Eleanor)</td>
<td>Being part of a team and getting on well Being part of a ‘dysfunctional’ family Being efficient and having a routine everyone sticks to Being part of a team facilitating hope Being able to cope with barriers and challenges as a team</td>
<td>Being part of a team</td>
<td></td>
</tr>
<tr>
<td>If a resident comes into the home and they’re quite distressed and they’re wanting to go home and not settling, and after those few weeks of settlement, and you see them happy and their families happy, because they’re happy, then that’s the hope you can give, and the hope you can have. (Jenny)</td>
<td>Seeing residents and their families happy despite coming into the home distressed and unsettled; being able to give hope to residents/families and hope for this to happen</td>
<td>Meeting needs</td>
<td></td>
</tr>
<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>Yeah, I think if you’re in a role for a long time, and you’re still not very hopeful, then I think maybe you need to be taking action somewhere along the line, because if you’ve been in the role for a long time or that home, and it’s not going along with the times or things aren’t changing, then you need to be sorting out something, or find somewhere where you can see things are changing. (Amanda)</td>
<td>Need to take action if in the role for a long time but not hopeful</td>
<td>Age and experience in caregiving</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Being in the role for a long time but things not changing, need to sort something</td>
<td>Individual factors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Finding somewhere where things are changing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Feeling</td>
<td>Holding</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>We’re so underappreciated. (Eleanor)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>But that’s the care profession in itself, it’s a job that you give give</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>give, and people are always taking, but you don’t get anything back. (Sarah)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoping for recognition and support</td>
<td>Feeling appreciated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling underappreciated</td>
<td></td>
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<tr>
<td>Underappreciation as part of role</td>
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<tr>
<td>Giving as part of the role and feeling taken from</td>
<td></td>
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<tr>
<td>Just hoping you’re never going to work with that sort of person, you’re</td>
<td></td>
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<tr>
<td>never going to have that sort of person alongside you.</td>
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<tr>
<td>Hopeful that everyone who comes through the door is caring and</td>
<td></td>
<td></td>
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<tr>
<td>compassionate and they’re here because of the love of the job. Not</td>
<td></td>
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<tr>
<td>because they want a pay package at the end of the month, because they’ve</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>got their mortgage or their rent or their council tax to pay.</td>
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<tr>
<td>I’ve always said, you can’t do this job for money, you’ve got to have</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>something in your heart. (Bethany)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoping to not work with someone who does not care about the role</td>
<td>Holding particular attitudes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoping to work with people who are caring, compassionate and love the job</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not being able to do the role if the only motivation is money</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing to have something in your heart to do the role</td>
<td></td>
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</table>
Appendix P: Epistemological Statement

Acknowledgement of the researcher’s personal perspective and its impact on the way research is approached and conducted is an important aspect of the research process.

The objective of this statement is to explore underlying ontological and epistemological assumptions which may have contributed to the conduct of the current research. Ontology is concerned with the meaning of reality for the researcher, whereas epistemology is concerned with the exploration of such reality (Guba, 1990). Consequently, this leads to choices regarding which methodology should be selected; the selection being dependent on the how the researcher wishes to examine reality.

The purpose of this was to provide a more balanced, holistic perspective of caregiving in literature that places an overwhelming emphasis on negative aspects, such as burnout. Although caregiving in such settings is acknowledged to be challenging, it is important to consider the whole experience of a professional caregiver in a context where turnover is high and staff are often undervalued. In order to understand such a subjective and context-dependent experience, it was felt a qualitative approach would be required.

The following discussion describes two different stances that were considered and the rationale for the approach taken.

A positive stance suggests the use of hypothesis testing and experiments can uncover an objective truth. Emphasis is placed on objectivity and assumes researcher bias will not influence the research process (Ponterotto, 2005). Therefore, due to the reductionist nature of this approach the positivist stance was rejected for the current study.

Additionally, due to the qualitative nature of the research being conducted, a positivist
stance, usually associated with quantitative methodology (Willig, 2001) was not considered appropriate.

A constructivist stance is relativist; and assumes there is not an objective truth to be uncovered and truth is a social reality (Guba & Lincoln, 1994). A constructivist stance also assumes individuals form their own reality, consequently there are many realities which are both diverse and subjective. The constructivist approach refers to learning how and to what extent an individual’s experience is immersed in social situations and relationships (Charmaz, 2006).

The constructivist stance also recognises that the researcher’s views and knowledge of the world will impact upon how they understand a participant’s experience, so the understanding is an interpretation of a participant’s experience (Charmaz, 2006). Hence analysis is situated in the context of place, time, situation and culture, and collaboratively constructed by both the research participant and researcher (Charmaz, 2006). As such acknowledgement of researcher reflexivity was necessary, i.e. the ability to reflect upon experience relating to the research and allow the self to be brought into the process (Charmaz, 2006). The researcher had previously worked in care homes, experiencing attachment with care-recipients and a sense of satisfaction whilst in the context of resource difficulties. The researcher was also aware of recent media coverage of poor practise and abuse in care homes, and had concerns about potential hopelessness amongst care staff. These experiences and thoughts could have influenced the conduction of interviews and analysis, and are therefore important to consider.

Acknowledgement of the researcher’s reflexivity and the social context in which caregiving is situated allowed a natural progression and corresponded with a
constructivist stance. The present study sought to understand and build a theory regarding how professional caregivers in residential dementia care settings maintain hope; subsequently this was approached from a constructivist perspective.

After examining the diverse qualitative methods available, constructivist Grounded Theory (GT) was selected as the most appropriate methodology to address the research questions of the current study. Thematic Analysis and Interpretative Phenomenological Analysis (IPA) were also considered as methods, and are reflected upon below.

**Thematic Analysis**

Thematic analysis involves categorising qualitative data and describing aspects of data (Pistrang & Barker, 2010). This aims to identify a set of common themes across data yielded from participant accounts, rather than acknowledging their individual experiences (Anderson, 2007). Thematic analysis may limit the researchers’ depth of understanding of individual experiences due to utilisation of minimal interpretation. The present study intends to gain an understanding and develop a theory regarding how professional caregivers maintain hope within their caregiving role, rather than a description of experience, accordingly Thematic Analysis was rejected.

**IPA**

IPA seeks to understand the individual experience and subjective meaning of those experiences for each participant (Smith & Osborn, 2008). Three areas of philosophical knowledge underpin IPA; phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). Phenomenology is the appraisal of an individual subjective experience, rather than an objective review of experience (Smith et al., 2009). Hermeneutics is the process of interpretation within phenomenology, while
acknowledging that individuals interpret their own experience, so their account reflects the way the event is borne and understood (Smith et al., 2009). Idiography refers to specific aspects of an individual’s experience and acknowledges the importance of an event unique to the individual (Smith et al., 2009).

The present study aspired to develop a theory which could be generalised for professional caregiving in residential dementia care settings, rather than an exploration of individual experiences, consequently IPA was rejected.

**Constructivist GT**

Constructivist GT was considered the most suitable methodology for developing an understanding of how professional caregivers maintain hopefulness in residential dementia care settings. GT methods were first developed by Barney Glaser and Anselm Strauss (1967) as a way of developing theories from research grounded in data, inspiring methodological debates and numerous variations of GT, including constructivist GT.

Constructivist GT aims to develop a theoretical understanding of a phenomenon, whilst including the social context in which the research is conducted (Charmaz, 2006). There are two stages of sampling in constructivist GT. The first stage, initial sampling, is where the researcher utilises an inclusion and exclusion criteria. The second stage, theoretical sampling, is used to explore emerging categories from initial coding.

Interview schedules are adapted and a heterogenous sample is sought to clarify gaps in emerging theory (Charmaz, 2006). Three stages of coding: initial, focused and theoretical are used as constructivist GT methods to develop an emergent theory.

Comparative data may be uncovered to find hidden properties of categories from the
coding process, and the researcher attempts to attain theoretical saturation.

Consequently, analysis runs in conjunction with data collection to clarify gaps in emerging theory, and is described as a central feature of GT (Glaser & Strauss, 1967). Theoretical saturation occurs when no new dimensions or properties are emerging (Holton, 2007), and further collection of data will not add to emerging theory (Charmaz, 2008).

Whilst utilising constructivist GT, the researcher assumes a reflexive stance towards the research process, considering how the researcher’s interpretation may impact analysis and theory building (Charmaz, 2006). When reflecting upon the different methodologies available, constructivist GT was found to be the most suitable methodology for the present study, aligning with the constructivist stance that had been taken.
Epistemology Statement References


Appendix Q: Reflective Statement

The Research Topic

My interest in dementia was ignited when I began volunteering in a residential dementia care home while studying for A-levels. I previously had no awareness of dementia, however having a mentor who was passionate about her work allowed my own interest to blossom. At this point I knew dementia care was a primary area of interest for me and something I would want to factor into my career.

Before beginning the clinical psychology doctorate, I was given the opportunity to help Dr Emma Wolverson and Dr Chris Clarke scope literature for a book which has since been published. The focus was Positive Psychology and people living with dementia; I was delighted to have the opportunity to contribute to work of such personal significance. This consolidated my interest in research relating to dementia, and I knew Emma and Chris were the perfect supervisors for me as they too are advocates for the notion of living well with dementia. I relished sharing in their views and opinions and enjoyed spending time with people who are passionate about this topic.

When considering options for my first research proposal I was certain I wanted to conduct research on people living with dementia. Through discussions with Emma and Chris I was drawn to a study examining professional caregivers and the direct impact they have on people living with dementia, and could appreciate the potential value of this. Having seen the significant gap in the literature, I felt such an important yet undervalued profession needed to be explored. Choosing a Positive Psychology topic was intriguing, and due to the low volume of literature the options were extensive. My
interest in hope had developed when scoping the literature for Emma and Chris’s book, and this was a natural focus for my own research topic.

Methodology

During my undergraduate degree, it appeared the only viable research option was quantitative research. I conducted quantitative research with people living with dementia, however their personalities and experiences were lost in numbers and ideas that did not particularly resonate with me; i.e. their cognition levels. When I commenced the clinical psychology doctorate I knew I wanted to attempt qualitative research, despite feeling unprepared for this step.

After speaking with Emma and Chris I wanted to go a step beyond exploring experiences; I wanted to build a theory to explain hope in professional caregivers, with a view to achieving something tangible and positive for residential care. This immediately excluded methodologies such as Interpretative Phenomenological Analysis; a worrying notion given this approach was being used by the majority of my peers. It felt safer to adopt an approach others were using and have the benefit of a potential support network; yet I knew this method would not answer my research questions. Constructivist Grounded Theory was the most suitable and logical option for me to utilise (please see Appendix X for further discussion).

If other researchers were to embark on a similar project, I would urge them to ask questions and seek out people using their chosen methodology. Choosing an uncommon methodology within your peer group can feel isolating, but there are always other researchers you can seek advice from. A meeting with a colleague in the nursing department who recently used Grounded Theory for his PhD was a valuable experience,
this pointed me in the right direction for further reading; and an overview with Emma and Chris helped me get started.

**Recruitment**

As recruitment was going to be one of the most difficult aspects of conducting research, I attempted to make contact with care home managers in the initial stages of the process. The first positive response I had via telephone was a care home manager who asked me to send the details of the study through email. Unfortunately, a few weeks later I discovered I had sent the details to the wrong email address. Going forward I will double check the spelling of an email address, and contact the addressee by telephone to check receipt. This seemed like a major setback, and unfortunately once the email had been sent to the right address, time passed very quickly with no response.

I felt unsure of how to achieve the correct balance between constant reminders and taking a step back, which could have led to being forgotten. After speaking to Emma and Chris I knew I needed to be more persistent, and accepted that care home managers are extremely busy and may need a reminder. Once the care home manager had approved the study, I assumed my next obstacle would be securing staff to take part in the research. Fortunately, this was not an issue, but arranging a time when six to eight people could participate in the focus group proved a challenge. Only a certain amount of staff members could be away from their units at one time, and I understood staff would have to be willing to stay after their shift in order to take part. I knew I would be obliged to be persistent again, so following a discussion with Chris I decided I would go to the care home in person. I needed to become a familiar face in the care home, and achieved this by dropping in and having informal conversations with staff. This
continued throughout individual interview recruitment, and is certainly something I would recommend to anyone conducting research in a care home. Administrative staff knew my name and were willing to help me contact staff members to arrange interviews, this proved to be invaluable.

**Interviews and Analysis**

I learnt that gaining feedback for an interview schedule was worthwhile, and contacted individuals I worked with in a care home to help remove jargon from the questions. Rehearsing the focus group with colleagues was also beneficial as this enabled me to practice including all participants and check timings.

When I began conducting interviews, my passion was reignited; I thoroughly enjoyed each interview and time spent in the care home units with both staff and residents. I felt comfortable in this space and this allowed me to rediscover why I had embarked on this project; a facet which had wavered during a lengthy process, involving a drawn-out ethics application and long waits for email replies.

A feature I found particularly surprising was the length of time it took to transcribe an interview; a typically quick typist, I did not expect the sheer amount of time it would take to complete this task. Despite this becoming tiresome at times, it allowed me to immerse myself in the data, and hear things I may have missed during the interview. This was really helpful in the continuous task of memo writing.

Constructivist Grounded Theory methodology involves conducting interviews and analysis in parallel. Therefore, each interview should be coded before the next interview is conducted, to allow theoretical sampling and adjustment of the interview schedule. This became difficult and impractical on occasion, for example when two staff members
were able to meet with me on one afternoon or morning. This removed the time required
to transcribe and code the interview ahead of conducting the next one. However, writing
memos throughout the interview helped me notice significant aspects which were
important to ask the following participant. With more time, I would have preferred to
fully transcribe and code each interview before conducting the next, however as time
was a limitation, this was not possible for the study.

Write-Up

Discovering an emergent theory was exciting; and I was determined to give the research
the attention it deserved. Whilst writing up the research, I had a consistent sense of not
being good enough, I was desperate for the research to have an impact and did not feel I
had the skills to achieve this. Through discussion with Emma and Chris, and their
supportive ‘pep’ talks I was able to view this as my research, and see my insecurity as a
reflection of ‘wanting to get it right’. As a researcher who has conducted interviews and
spent time with participants, telling their story adequately becomes important. We have
been fortunate enough to hear how participants think and feel, and this leaves us in a
privileged position, reflection on this is important in order to progress with writing up
research.

Systematic Literature Review

Choosing a topic for the systematic literature review felt lengthy and difficult, and I was
not sure which topic would link appropriately to my empirical paper. Due to the lack of
literature relating to professional dementia caregivers, and the concentration on negative
aspects, it became clear the focus needed to be balanced and holistic. Through
discussion with my supervisors and by scoping the literature base, I settled on a topic
encapsulating the need for a holistic perspective of caregiving in residential dementia care settings. The process was iterative, and although this was frustrating at times, it eventually evolved a set of questions and criteria to address my aims. Synthesising the data was an overwhelming experience due to the heterogeneous nature of the literature; at times I had very little idea of where to go next. Despite the long and at times frustrating process, I came to appreciate the importance of such a review in what is a fundamentally negative literature base; I became passionate about filling a gap and providing a holistic perspective of caregiving.

### Choice of Journals

For my empirical paper, I chose to write for the journal of ‘Aging & Mental Health’. This is a well-respected peer reviewed journal. The journal welcomes research relating to development of services which can be directed at improving the mental health of older adults. Due to my exploration of how hope can directly impact the quality of care provided in residential dementia settings, I felt this was an appropriate journal to choose.

For my systematic literature review, I chose to write for the journal of ‘International Psychogeriatrics’. This peer reviewed journal is likewise highly respected and publishes papers relating to ageing and mental health. The journal also publishes literature reviews, consequently a review giving a balanced and holistic perspective of caregiving in residential dementia settings seemed to be appropriate.

### Final Reflections

It is an emotive experience to reflect upon how I arrived where I am now; a passion for working with people facing dementia pushed me in the direction of a career in this area,
and afforded me the opportunity to begin clinical psychology training. Since then my
knowledge and passion has grown continuously, and conducting research in this field
has helped me to see older adults and dementia as an area where I need to be a
practicing clinical psychologist. The research journey has been difficult, and
occasionally overwhelming, nonetheless it has allowed me to grow as both a researcher
and clinician; an invaluable experience.