Oxford Doctoral Course in Clinical Psychology

UNDERSTANDING THE PSYCHOLOGICAL HEALTH AND EXPERIENCES OF DEMENTIA CARE STAFF

Alice Coates

A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology, validated by the University of Oxford

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Understanding the Psychological Health and Experiences of Dementia Care Staff

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Abstract

Care work is emotionally and physically demanding and is coupled with organisational challenges. As such, care work has been associated with emotional exhaustion which not only negatively impacts staff but also the care that they provide. Greater understanding of the psychological health of dementia care staff and their perceptions of their work will provide insights into how this group may be better supported.

The first paper provides a review of the literature relating to psychological outcomes in dementia care staff. The literature identified was viewed in terms of an existing model of psychological health, the BASIC Ph, with the aim of evaluating the evidence and enhancing understanding of psychological health in this group. The utility of this model was also evaluated. The model highlighted areas for potential intervention as well as those for future research. Clinical implications for Clinical Psychologists were also discussed.

The second paper aimed to increase understanding of the experiences of dementia care assistants who perceived themselves to be competent in their role. Eight care assistants who had high levels of self-efficacy were interviewed. Interpretative Phenomenological Analysis (IPA) revealed four superordinate themes. Accounts of experiencing dilemmas provided important contextual information and constituted the

first superordinate theme. The second theme ‘togetherness and connection’ described participants’ experience of the need for support, closeness and the value of engaging with older people with dementia. The third theme encompassed the attunement between care assistants and the older people for whom they cared and described empathy, personal perspective-taking and circularity of emotion as guides to care. The final theme ‘caring as part of life’ described the link between caring and identity as well as a genuine interest in people, an accepting attitude and motivation to care. These themes provide fruitful areas for further research and have implications for care staff training.

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Paper B

Oxford Doctoral Course in Clinical Psychology

An Integrative Review of Psychological Health in Dementia Care Staff: Evaluating the Applicability of the BASIC Ph Model

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An Integrative Review of Psychological Health in Dementia Care Staff: Evaluating the Applicability of the BASIC Ph Model

Abstract

Care work has been associated with negative psychological outcomes. However, many staff continue to have good psychological health in spite of the challenges they face. Increased understanding of the factors associated with psychological health will highlight how this may be enhanced in dementia care staff. This review aimed to systematically identify literature relating to psychological outcomes in dementia care staff. Twenty-three articles were identified. This literature was then viewed in terms of a broad model of psychological health, the BASIC Ph. The BASIC Ph model provided a means by which factors associated with the psychological health of care staff could be readily categorised. As such, the model served to increase understanding of the processes and factors associated with the maintenance of psychological health in this group. Elements of the BASIC Ph model that have not been considered by the research to date highlight important avenues for future research.

Keywords: dementia, care home, care staff, psychological health

Proposed Journal: Dementia: The International Journal of Social Research and Practice

Introduction

Background

By 2017, it is estimated that 444,000 older people in the UK will be living in care homes[1] (Laing & Buisson, 2007) of whom 80% are predicted to have dementia (Quince, 2013). Given that people with dementia are being supported to live at home for longer, they are likely to be entering care homes at a later stage in their condition, typically when informal and formal community support is insufficient (World Health Organisation [WHO], 2012). In future, therefore, care staff[2] will increasingly be caring for clients with the complex needs and high levels of dependency associated with more advanced dementia. This has implications for care staff ratios, training and support (Macdonald & Cooper, 2007).

Care work has been associated with poor pay (Low Pay Commission, 2015), long hours (Mercer, Heacock, & Beck, 1994), insufficient training (Eborall, Fenton, & Woodrow, 2010) and limited room for career progression (Hussein, Manthorpe, & Stevens, 2011). Furthermore, care work is both emotionally and physically demanding (e.g. Edvardsson, Sandman, & Nay, 2009; Goergen, 2001). Given organisational challenges and the complex needs of residents, it is perhaps unsurprising that care work has been associated with stress (Engström, Ljunggren, Lindqvist, & Carlsson, 2006) and emotional exhaustion (Kokkonen, Cheston, Dallos, & Smart, 2014). Additionally, psychological morbidity in staff is proposed to negatively impact on the care that they

[1] The regulatory body for health and social care in England, the Care Quality Commission (CQC), defines a care home as a place where personal care and accommodation are provided together. Care homes offer care and support throughout the day and night and staff help with washing, dressing, at meal times and with using the toilet (CQC, 2014).

[2] For consistency, the term 'care staff' will be used throughout to refer to individuals, with varying levels of qualification, who undertake paid work in care homes for older people with dementia. However, it is recognised that a number of alternative terms could have been used.

provide (Todd & Watts, 2005). The evidence therefore suggests that it is, and will be, increasingly important to consider the psychological health of dementia care staff.

Whilst high levels of emotional exhaustion and burnout in care staff have been reported (Kokkonen et al., 2014), prevalence estimates are mixed with figures of those at risk of developing burnout, ranging from 5-37% (Pitfield, Shahriyarmolki, & Livingston, 2011). Overall, evidence suggests that, despite the challenges they face, many care staff do not experience high levels of emotional or psychological distress but maintain good psychological health (e.g. Heyns, Venter, Esterhuyse, Bam, & Odendaal, 2003).

Models have attempted to conceptualise the factors associated with negative psychological outcomes in care staff (e.g. Abrahamson, Suitor, & Pillemer, 2009; Cohen-Mansfield, 1995). However, existing models adopt a negative frame of reference which may not provide a comprehensive explanation of psychological health and adaptive functioning (Sheldon & King, 2001). Thus, they may not explain why some care staff do not experience negative psychological outcomes but maintain good psychological health in spite of the challenges they face.

Psychological Health

Psychological health has been broadly defined as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (WHO, 2014, p. 1). This definition of psychological health moves beyond the mere "absence of disease or infirmity" and links to concepts of resilience and coping. The importance of resilience, coping and psychological health has been highlighted as a priority across UK Government Departments (British Psychological Society, 2009).

Psychological Health in Care Staff

Within a nursing context, the possible benefits of enhancing psychological health, rather than solely decreasing negative stressors, have been expounded (Garrosa, Moreno-Jimenez, Liang, & González, 2008). Despite the potential benefits of understanding psychological health, research considering the skills and resources of dementia care staff that enable them to continue to function in a positive way is lacking (Testad, Mikkelsen, Ballard, & Aarsland, 2010). However, in light of the increasing challenges faced by care staff, a review of factors affecting psychological health in this group is pertinent.

Given the relative lack of literature regarding psychological outcomes in care staff, drawing on an existing model may serve to increase understanding of psychological health in this population. Whilst frameworks have been proposed to understand concepts such as resilience in informal carers (e.g. Cherry et al., 2013), these encompass relationship and familial factors that are not relevant to professional care staff.

This review has chosen to explore the BASIC Ph model which uses the terms resilience and coping, key to any definition of psychological health, but presents a broader framework within which psychological health can be conceptualised. The model has been applied to nursing students (Hadary, 2013), to businesses and organisations (Elmaliach, 2013) and cross-culturally (e.g. Shacham, 2013). It is therefore well placed to consider psychological health in a culturally diverse workforce (Hussein, Manthorpe, & Stevens, 2010; Luff, Ferreira, & Meyer, 2011) and the organisational contexts in which care staff exist in the UK.

The BASIC Ph Model of Coping and Resiliency

The BASIC Ph model emerged from research studying individuals under prolonged stress who continued to function well (Lahad & Leykin,2013). The authors

highlight that, under stress, individuals employ different coping mechanisms. The model is proposed to provide a means of understanding how coping factors and processes can promote psychological and physical health in spite of stress. As such, the BASIC Ph is described as a meta-model for understanding coping and resilience (Lahad & Leykin, 2013), one that is broad and may increase our understanding of psychological health.

Table 1

Elements of the BASIC Ph Model with Examples of Underlying Constructs and Theoretical Bases

B	**A**	**S**	**I**	**C**	**Ph**
Beliefs	Affect	Social	Imagination	Cognition	Physical
Self, ideology	Emotions	Role, others, organisation	Intuition, humour	Reality, knowledge	Action, practical
Maslow (1962); Frankl (1963)	Freud (1933); Rodgers (1951)	Erikson (1963); Adler (1956)	Jung (1977); De Bono (1992)	Lazarus & Folkman (1984)	Pavlov (1927); Watson (1924)

Note. Adapted from Lahad & Leykin (2013). References found in Appendix A.

The integrative BASIC Ph model proposes six fundamental elements of coping that are derived from theoretical attempts to describe the "human struggle to survive in… demanding environment(s)" (Lahad & Leykin, 2013, p.10) (See Table 1.). The model postulates that, on the basis of innate tendencies and past experiences, individuals develop their own configuration of elements which constitutes their preferred mode of coping; within the model, resilience is therefore conceptualised as individual differences and experiences that aid people to cope positively in the face of adversity. Conceptualising resiliency and coping in this integrative, multi-faceted way allows for a

comprehensive and nuanced account of coping and the maintenance of psychological health in the face of a challenging work environment.

Summary

To date there has been a lack of focus on psychological health in care staff. Reviews have considered turnover (Chenoweth, Jeon, Merlyn, & Brodaty, 2010), satisfaction (Manthorpe, 2014) as well as interventions to increase resilience (Elliott, Scott, Stirling, Martin, & Robinson, 2012) and reduce burnout (Westermann, Kozak, Harling, & Nienhaus, 2014). However, these do not capture the ways in which staff maintain psychological health in spite of the challenges they face.

Viewing existing literature relating to psychological outcomes in dementia care staff in terms of the BASIC Ph model may highlight processes and factors associated with the maintenance of psychological health in this group. Increasing understanding of these factors will provide insight into how care staff psychological health could be enhanced, which in turn will positively impact the care they provide (Heyns et al., 2003; Zimmerman et al., 2005).

Aims and Objectives

This review aims to systematically identify literature relating to psychological health in dementia care staff. Due to the limited literature relating to wellbeing, the review will encompass both positive[3] and negative[4] psychological outcomes in this group. It is noted that the elements of the BASIC Ph model are not unitary concepts. However, to facilitate understanding of the literature in relation to the model there is a need to categorise. The relevant literature will be critically evaluated and the extent to which it fits with the BASIC Ph model will be considered.

[3] Satisfaction was conceptualised as a process rather than an outcome and was therefore not included.
[4] There is an expanding literature regarding turnover in care staff. However, inferring psychological health from turnover is not methodologically sound. Turnover and retention were therefore not included.

Method

Search Methods

A systematic search of the literature was conducted using five electronic databases (CINAHL, BNI, PsycINFO, Medline, Social Care Online[5]). Each literature search combined keywords relating to older people, dementia, care homes and care staff as well as psychological health including positive and negative outcomes (Appendix B).

In light of the number of articles that related to nursing homes but that did not specify that residents had dementia, a further advanced search that excluded keywords relating to dementia was conducted on four databases[6] (See Appendix B). Following the initial literature searches, a subsequent hand search was carried out. This was followed by a search of the reference lists of full-text studies.

The resulting titles and abstracts were scanned to identify potentially relevant articles. Articles were evaluated against the following criteria.

Inclusion Criteria

- Published in a peer reviewed journal.
- Provided qualitative or quantitative data on intrinsic processes or factors associated with positive and negative outcomes in the psychological health of staff providing direct care for older people with dementia and working in care homes or equivalent settings[7].

[5] Social Care Online was selected over other databases in order to capture literature emerging from Social Care disciplines.
[6] A search through Social Care Online was attempted; however, it was not viable due to the number of unrelated results generated.
[7] Research indicates that up to 80% of nursing home residents have a form of dementia (Quince, 2013). Therefore, articles detailing outcomes in these settings which do not specifically note dementia care were also included.

Exclusion Criteria

- Related solely to staff who hold professional qualifications[8] (e.g. registered nurses; social workers).
- Related solely to care staff working in a hospital setting.
- Related to staff providing domiciliary care[9].
- Were not published in English.
- Constituted 'grey literature'.

The full texts of identified articles that met the inclusion and exclusion criteria were obtained. The literature identified was categorised into the elements of the BASIC Ph model by the author. This process was repeated by an expert in the field.

Results

The initial keyword searches identified 164 unique articles across PsychInfo, BNI, CINAHL and Medline. Social Care Online generated 684 articles. The titles and abstracts of these papers were reviewed and 38 articles were identified. Upon further reading, it was apparent that 29 articles did not meet all the criteria for inclusion. This resulted in a total of nine articles.

In the second searches, a further 579 articles were identified of which four met the criteria for inclusion. A further 10 articles were identified from hand searches, making a total of 23 articles. (See Appendix C for a flow chart of the data gathering process).

Data were extracted from the identified articles and key information was summarised. The results of the literature search were tabulated (Appendix D). The

[8] The UK care workforces is made up of 74% direct care staff, 10% of whom are without any qualification and the majority of whom are without professional qualifications (Hussein, 2010). Literature focusing solely on staff with professional qualifications was therefore not deemed representative.

[9] Whilst research has suggested equivalent staff outcomes across some care work settings (Moniz-Cook, Clin, Millington, & Silver, 1997), articles relating to dementia care staff in domiciliary care were excluded due to the differing organisational and situational factors associated with this work.

articles identified were classified according to the six elements of the BASIC Ph model. Leykin and Lahad's (2013) categorisation of coping processes identified by Skinner and colleagues' (2003) meta-analysis acted as a guide to assist in classification (Appendix F). Inter-rater concordance in categorisation was 82.6%.

Lahad and Leykin (2013) highlight overlap within the model, with some factors promoting psychological health correlating with more than one element of the model. Six articles provided data compatible with more than one element of the model. Studies were therefore categorised according to their primary findings. However, due to the identified overlap, findings may be referred to in other relevant sections.

Literature in relation to the BASIC Ph model

Beliefs

'Beliefs' are proposed to reflect an individual's ideology, their attitudes and sense of self. As such, self-reliance, optimism, self-belief and self-esteem are all proposed as factors within the 'belief' element of the model.

Of the articles identified by the literature search, five were found to primarily relate to the 'beliefs' element of the BASIC Ph model. All the articles related to negative outcomes in care staff and were cross-sectional in design. Of the articles, one related to sense of coherence (Heyns et al., 2003), two to self-efficacy (Duffy, Oyebode, & Allen, 2009; Evers, Tomic, & Brouwers, 2001) and one to perceived mastery (Testad et al., 2010). A further article investigated the association between attitude and outcome (Zimmerman et al., 2005).

Sense of coherence. An individual's sense of coherence, namely the comprehensibility, manageability and meaningfulness they ascribe to a situation, has been

found to impact upon the psychological health of dementia care staff in South Africa (Heyns et al., 2003); the research benefited from stipulating that all participants required a minimum amount of direct dementia care per week. Hierarchical regression analysis of data from 226 care staff found sense of coherence explained the greatest amount of variance in their levels of emotional exhaustion (3.86%) and depersonalisation (7.23%). Perceived fortitude, which is proposed to reflect a particular philosophy on life (Strümpfer, 1995), also accounted for some variance (1.71%) (Heyns et al., 2003). Whilst the amount of variance accounted for and the effect sizes were small, the results endorse the potential importance of 'sense-making' and ideology in contributing to the psychological health of care staff.

Self-efficacy. Research has also identified a relationship between care staff's levels of self-efficacy, referring to the belief that one has the ability to accomplish specific goals (Bandura, 1977), and their levels of burnout (Duffy et al., 2009). In a cross-sectional survey of dementia care staff working solely in UK care homes, levels of self-efficacy were found to predict all dimensions of burnout (Duffy et al., 2009) as measured by the Maslach Burnout Inventory (MBI; Maslach, Jackson, & Leiter, 1986). With a sample of 61 and three predictor variables, the study would have benefitted from a larger sample size for regression analysis (Field, 2013). Nevertheless, the results indicate the probable role of perceived self-efficacy in maintaining psychological health.

This finding is supported by Evers, Tomic and Brouwers (2001) who measured self-efficacy in a large sample of 551 care staff working in nursing homes in the Netherlands. Perceived self-efficacy was found to be a significant predictor of the personal accomplishment subscale of the MBI (Maslach et al., 1986); however, whilst the MBI is widely used and independently validated, of the three subscales this is the least able to distinguish burnout (Schaufeli, Bakker, Hoogduin, Schaap, & Kladler, 2001). The

authors also provide a limited description of participants' job roles, thus restricting cross-study comparison. Further, the measure of perceived self-efficacy was adapted from the educational domain and is not validated for this population. However, despite using a different measure, the results demonstrate consistency with the findings of Duffy and colleagues (2009).

Perceived mastery. Perceived mastery, a concept related to self-efficacy, has also been associated with the psychological health of dementia care staff (Testad et al., 2010). In a study of staff working in nursing homes in Norway, perceived mastery and control at work were found to have a significant negative association with psychological distress. Along with leadership, these two predictors accounted for 34.2% of the variance in psychological distress (Testad et al., 2010). Importantly, resident factors that may impact on staff's perceived mastery, such as levels of agitation, were accounted for; agitation as a predictor did not improve the model and the variance remained at 35.2%. Whilst the majority of the sample were nurses and so not representative of the UK dementia workforce (Hussein, 2010), the potential benefit of increasing an individual's perception of control and mastery is highlighted (Testad et al., 2010).

Attitudes. Zimmerman and colleagues (2005) investigated the impact of attitudes on work stress in 154 nursing home and assisted living staff in the USA. Participants worked in a variety of roles. However, the vast majority (88.3%) were care assistants, which is representative of the UK workforce (Hussein, 2010). Results revealed that the highest levels of stress were reported by those working for 1-2 two years. The same group were also more likely to report hopeful or person-centred attitudes. Whilst analyses did not directly test these variables, the potential association between person-centred attitudes and work stress is a pertinent area for further research, particularly in light of the drive towards person-centred care in care homes.

Summary. Of the identified studies, all were cross-sectional and thus causality cannot be inferred. Furthermore, the research originated from a range of countries and spanned a variety of work settings with only one conducted solely in dementia care homes in the UK, which limits generalizability and cross-study comparison. Nevertheless, the research findings point to the impact of individual's 'sense-making' and ideology (Heyns et al., 2003) as well as self-belief (Duffy et al., 2009; Evers et al., 2001; Testad et al., 2010) on the psychological health of care staff. Research has also indicated the potential impact of perception and attitudes on this group (Zimmerman et al., 2005). Coping factors discussed in the 'beliefs' element of the model, such as faith and spirituality, which have not been researched, may provide a fruitful area of future investigation.

Affect

The 'affect' element of the model encapsulates the emotions that an individual experiences in response to adversity, as well as other related behaviours, including emotional approach and emotional expression (Lahad & Leykin, 2013). Two articles were categorised as reflecting the 'affect' element of the model. Both articles related to negative psychological outcome. One adopted a between-group design to consider the association between burnout and empathy (Åström, Nilsson, Norberg, Sandman, & Winblad, 1991). The other used a longitudinal design to investigate a shift in feeling related to work over time (Schmidt, Dichter, Bartholomeyczik, & Hasselhorn, 2014).

Empathy. Empathy refers to an individual's ability to understand or identify with the feelings of another (Colman, 2009) and has been associated with burnout in caring professions (Pines, Aronson, & Kafry, 1981). Åstrom and colleagues (1991) purposively sampled staff with either high or low levels of burnout and empathy across three settings. The regression analyses were potentially compromised by the heterogeneous nature of the

sample and a relatively small sample size (N=62). Nevertheless, findings revealed lower levels of empathy and a less positive attitude correlated with higher levels of burnout. Conversely, a more positive attitude (r=0.50) and higher levels of empathy (r=-0.32) were moderately associated with lower levels of burnout. The results contradict those from past research where higher levels of empathy were associated with an increased risk of developing burnout due to a greater sensitivity to demands and a deeper involvement with patients (Maslach & Jackson, 1982). Further research investigating the link between empathy and burnout would therefore be beneficial (Åström et al., 1991).

Feelings relating to work. A relationship between staff's psychological health and a shift in their feelings regarding their work has been proposed. A longitudinal study found that nursing home staff in Germany, who shifted from being satisfied to dissatisfied over the 2 year study period, demonstrated negative change on measures of burnout and general health (Schmidt et al., 2014). Further, between-group comparisons indicated that deterioration in health was significantly more pronounced in staff who moved from being satisfied to dissatisfied than in staff who were dissatisfied at baseline and follow-up. The study benefited from a strong design and adequate sample size (N=305). However, 67% of the sample was made up of registered nurses, which is not representative of UK care homes (Hussein, 2010) and therefore limits generalizability. Nevertheless, the results do highlight a potential vulnerability to burnout arising from a shift in affect over time.

Summary. Only two research studies were categorised as reflecting the 'affect' element of the model. Furthermore, their focus, participants and settings were disparate. Nevertheless, the studies highlight a link between empathy and the psychological health of care staff. The present review did not consider satisfaction as an outcome. However, findings implicate a shift in levels of satisfaction as a factor influencing the psychological health of care staff. The impact of other coping processes encompassed within the affect

element of the model, such as emotional expression, have not been explored in this group and so may provide an avenue for future research.

Social

The 'social' element of the BASIC Ph model reflects factors relating to an individual's social role as well as their interactions with others and their organisations; thus, for example, seeking and utilising social support would be subsumed within the 'social' element of the model.

Of the identified articles, eight were categorised as reflecting the 'social' element of the model. One of these purported to relate to positive outcomes. The remainder related to negative outcomes. Six related to relationships in the workplace (Abrahamson et al., 2009; Cole, Scott, & Skelton-Robinson, 2000; Schaefer & Moos, 1996; te Boekhorst, Willemse, Depla, Eefsting, & Pot, 2008; van den Berg, Landeweerd, Tummers, & van Merode, 2006; Visser et al., 2008), one to autonomy (Gruss, McCann, Edelman, & Farran, 2004) and one to perceived caring climate (Edvardsson et al., 2009). Six had a cross-sectional correlational design, one was longitudinal and one a between-group analysis.

Workplace social support. The importance of workplace social support in the psychological health of dementia care staff has been highlighted in six studies. For instance, in nursing and group living homes in the Netherlands, social support from co-workers was identified as a significant predictor of all three subscales of the MBI (te Boekhorst et al., 2008). Further, comparison between nursing and group living home staff indicated that the higher level of burnout identified in nursing home settings was due to the greater demands, reduced perceived control and less social support in this

environment (te Boekhorst et al., 2008). This highlights the need to explore social support, particularly in the nursing home setting.

The impact of social support on the psychological health of care staff has been emphasised by other researchers (Cole et al., 2000; van den Berg et al., 2006). A large-scale study of 1,024 care staff working in nursing home and hospital settings explored predictors of burnout using regression analysis. Whilst the sample included staff working in both hospital and nursing home settings, separate analyses allowed low social support and high workload to be identified as predictors of emotional exhaustion specifically in a nursing home setting (van den Berg et al., 2006). However, whilst workload accounted for 20% of the variance in burnout, social support only accounted for 5% highlighting the role of other variables.

Cole and colleagues (2000) reiterated this finding measuring wellbeing using the General Health Questionnaire (GHQ-28; Goldberg & Hillier, 1979) in staff working in UK nursing home and mental health settings. Across the sample, social support was significantly associated with wellbeing. However, whilst exploring wellbeing, and thus appearing to adopt a positive frame of reference, the GHQ is a screening instrument for psychological distress and therefore relates to negative psychological outcomes. Nevertheless, in comparing the two groups, staff working in nursing homes were found to rate themselves as having less support and lower levels of wellbeing, highlighting the need to explore this association further.

The benefit of staff sharing stressful experiences with colleagues has been expounded, with fewer opportunities to discuss difficulties and ethical conflicts significantly associated with job strain (Edvardsson et al., 2009). However, over 30% of nursing home staff do not believe they have adequate opportunity to discuss the

psychological stress of their work (Brodaty, Draper, & Low, 2003). In relation to this, research has investigated the impact of supervisory relationships on staff working in nursing and residential care in the USA (Schaefer & Moos, 1996). In a longitudinal study, staff relationships with supervisors were identified as significant predictors of depressed mood and negative physical symptoms at an 8 month follow-up (Schaefer & Moos, 1996); importantly, whilst the largest proportion were nursing assistants, the sample also encompassed a variety of professionals, including physicians, social workers and therapists, who may have had very different experiences and expectations of supervision. Additionally the research found that, whilst general job stressors correlated positively with job-related distress, patient care task stressors were associated with reduced job-related distress and depressed mood (Schaefer & Moos, 1996). Therefore, as well as highlighting the centrality of good working relationships, this research emphasises the impact of staff-resident relationships in influencing staff wellbeing.

Staff-relative relationships have also been associated with the psychological health of staff (Abrahamson et al., 2009). Structural equation modelling of data from 655 nurses and nursing assistants in America found conflict with residents' families to be positively associated with burnout. However, the burnout measure used was non-standardised and its reliability relatively poor (Cronbach's $\alpha = 0.58$) thus limiting the results.

Despite apparent corroboration for the positive impact of social support on the psychological health of care staff, research findings relating to this association are not unequivocal (e.g. Barber & Iwai, 1996; Visser et al., 2008). Visser and colleagues (2008) completed an intervention-based study in aged care facilities in Australia that evaluated the relative benefit of supplementing eight education sessions with four, 30 minute, peer support sessions; the education sessions focused on dementia, behavioural symptoms and

individualising care plans on the basis of a behavioural model. Peer support had no additive effect in reducing levels of staff burnout than education sessions alone. However, it was found to increase staff self-reported skills, knowledge and confidence in working with residents with dementia. The research benefited from a pre-test post-test design with a control group and follow-up data, as well as good characterisation of the residents. However, it was limited by a relatively small sample size (N=52) for a between-group analysis.

Perceived caring climate. Less positive perceptions of the caring climate, in a Swedish residential care setting, have been found to be associated with negative psychological health, namely job strain (Edvardsson et al., 2009); job strain is proposed to have external dimensions, such as lack of support and recognition, which foster internal feelings of irritation and frustration (Revicki, May, & Whitley, 1991). With four predictors, the sample size of 344 was adequate for linear regression analysis (Field, 2013). However, whilst perception of the caring environment of the care homes was found to have the largest independent association, all predictors only accounted for 19% of the variance, highlighting the role of other factors in contributing to strain. The findings were also restricted by the use of visual analogue scales which, whilst simple to employ, had limited reliability (Cronbach's α =0.49). Nevertheless, the research highlights the importance of care staff's perception of the emotio-cultural environment of care homes.

Autonomy. Research has also considered the impact of care staff perceptions of autonomy on their psychological health. For instance, decision authority has been found to be a significant predictor of burnout (te Boekhorst et al., 2008). Gruss and colleagues (2004) compared two dementia units in the USA, one un-renovated and one that had been renovated to create a more empowering environment and increase job autonomy. In the

renovated unit, staff reported greater empowering factors, participation and resources to do their job, as well as more resident-focused stressors. This was in contrast to staff working in a non-renovated unit who reported fewer empowering factors and more job-related stressors. The findings may be limited by the use of non-standardised structured questions to measure empowerment. Whilst the sample size was small (N=27), it was homogenous and suggested that an empowering environment and increased perceived autonomy impact on the focus of perceived stress. An increased focus on the resident is likely to have potential benefit for the residents for whom staff are caring.

Summary. Social support has been associated with reduced negative outcome in care staff (Edvardsson et al., 2009; Schaefer & Moos, 1996; van den Berg et al., 2006). However, these findings are not consistent (Visser et al., 2008). Further, the majority of the research has been cross-sectional, therefore limiting understanding of causality. Nevertheless, longitudinal research indicates a possible causal link between social support and burnout (e.g. Schaefer & Moos, 1996).

Future research may benefit from exploring the impact of the broader support staff gain from friends or family; whilst encompassed within this element of the BASIC Ph model, this has not been considered in research to date.

Imagination

Layad and Leykin (2013) propose that the 'imagination' category of the model encompasses strategies such as wishful thinking as well as creativity. Furthermore, coping by means of mental disengagement, distraction and detachment are also subsumed within the 'imagination' element of the model.

Of the identified articles, one was categorised as reflecting the 'imagination' element of the model (Brodaty et al., 2003). Findings from this article related to detachment from residents and adopted a cross-sectional design.

Detachment. Detachment has been highlighted as a possible mediator in the relationship between attitudes and strain in 253 care staff working solely in nursing home settings in Australia (Brodaty et al., 2003). The study benefited from good characterisation of the individuals being cared for as well as levels of staff's dementia training, which may have impacted on their level of engagement with residents. Findings revealed that care staff who hold more negative attitudes about residents report lower levels of strain. This association is hypothesised to be a consequence of less involvement with residents (Brodaty et al., 2003). The findings may point to disengaging from residents as a means of reducing strain in care staff.

Support for the potential protective function of disengagement can be inferred from research highlighting a link between increased empathy and burnout (Maslach & Jackson, 1982). However, these findings are in conflict with an association between higher levels of reciprocity and lower levels of burnout in care staff (Duffy et al., 2009) which suggest that detachment negatively impacts on the psychological health of care staff.

Summary. The literature review revealed one research study that was classified as relating to 'imagination'. This study had a cross-sectional design which limited inference about causality. Additionally, the possible protective function of detachment was not directly measured but rather was proposed by the authors to account for the association between attitudes and strains. Further research employing objective measurement of

engagement and disengagement with residents would be beneficial in elucidating if this constitutes a mediator between attitudes and psychological health.

As far as the author is aware, the impact of coping processes such as creativity, wishful thinking and imagination (Skinner et al., 2003) have not been investigated in dementia care staff. In light of emerging care practices, and the encouragement for staff to draw on creativity (Cutler, Kelly, & Silver, 2011), this may be a productive area for further research.

Cognition

Factors falling within the 'cognition' element include adopting a problem-focused approach as well as cognitive re-focus and re-evaluation. As such, this element demonstrates some overlap with well-known concepts from psychology coping literature (e.g. Lazarus & Folkman, 1984).

Of the identified articles, five were categorised as reflecting the 'cognition' element of the model. All of the articles considered negative outcomes in staff and all were cross-sectional. Two related to ambiguity (Barber & Iwai, 1996; Moniz-Cook et al., 1997), two to stress of conscience (Juthberg, Eriksson, Norberg, & Sundin, 2008; Saarnio, Sarvimäki, Laukkala, & Isola, 2012), and one to appraisal (Rodney, 2000).

Role ambiguity and role conflict. Barber and Iwai (1996), using hierarchical regression, found that role ambiguity and role conflict in staff working in long-term care facilities in the USA accounted for 47.1% of the variance in the intensity of emotional exhaustion; this represented more variance than that explained by caregiving involvement (16.2%), social support (4.4%) or staff characteristics (32.4%). Role ambiguity refers to the degree to which clear information regarding role expectations and consequences is absent (Barber & Iwai, 1996) and has been found to be significantly higher in nursing

homes than mental health settings (Cole et al., 2000). Role conflict, which describes the simultaneous occurrence of two or more pressures, was proposed to be more predictive of emotional exhaustion than role ambiguity (Barber & Iwai, 1996). However, given that the variables were entered into the analyses together under one umbrella term, 'work characteristics', it was not possible to identify their relative contributions. Whilst the sample size for completing regression analysis was relatively small (N=75), the findings highlight the potential impact of competing pressures on staff.

Related to role ambiguity, poor job clarity has also been associated with emotional exhaustion in staff (Moniz-Cook et al., 1997). Although the sample was specifically recruited from UK care homes, only 29% of the residents demonstrated behaviour suggestive of dementia and therefore it may not be possible to relate the results to the dementia care workforce. Nevertheless, an association between role conflict and clarity and emotional exhaustion is apparent. Future research may benefit from considering the role of coping processes, such as decision-making and problem-solving, that may link to role conflict and ambiguity.

Stress of conscience. Stress of conscience refers to staff's perceptions that they have been exposed to contradictory demands and have experienced shortcomings (Juthberg et al., 2008; Juthberg, Eriksson, Norberg, & Sundin, 2010; Saarnio et al., 2012). In a study conducted across wards, nursing homes and dementia care units in Finland, Saarnio and colleagues (2012) found stress of conscience was associated with increased work demands and staff feeling that they were not able to give their own families and loved ones the attention that they wanted. By extension, in a sample of 146 nurses and nursing assistants working in a variety of settings in Sweden, Juthberg and colleagues (2008) found a strong relationship between stress of conscience and burnout (r=0.66). The stress described as deriving from a troubled conscience may relate to the coping

processes of negotiation and being dual-focused, which are categorised as representing the 'cognition' element of the BASIC Ph model (Lahad & Leykin, 2013).

Appraisal. Rodney (2000) reported a significant association between the primary appraisal of challenge and the level of stress experienced by direct-care workers, care assistants and nurses working in nursing homes in Australia. Indeed, 32% of the variance in stress was associated with threat and challenge appraisal; a further 2% was accounted for by action and palliative coping, which better relates to the practical aspects of coping considered in the following section. Secondary appraisal, defined as the process by which a "person evaluates what, if anything, can be done to overcome or prevent harm or to improve the prospects for benefit" (Folkman, Lazarus, Gruen, & DeLongis, 1986, p.572), did not, however, explain variance in staff stress. Importantly, the levels of aggression that staff were exposed to, which may impact on threat and challenge appraisals, were accounted for in these analyses.

In support of these findings, appraisals of residents' physical and psychological aggression have been identified as significant predictors of both emotional exhaustion and depersonalisation, explaining 13% and 7% of the variance in these subscales respectively (Evers et al., 2001). The greater impact of psychological, rather than physical, aggression on burnout is hypothesised to be consequent to psychological aggression being less visible and, as such, less easily avoided (Evers et al., 2001). However, the findings may also reflect difficulties in making sense of less overt aggressive behaviour. In support, staff reported increased difficulty with behaviours they perceived as deliberately difficult, unpredictable or barely under their control (Brodaty et al., 2003). The impact of staff appraisal on psychological health is therefore highlighted.

Summary. Role ambiguity, role conflict, stress of conscience and appraisal were all categorised as relating to the 'cognition' element of the model. The identified studies were again limited by a cross-sectional design. Thus, for instance, it is not possible to ascertain if burnout impacts on appraisal and perceptions of role conflict or vice versa, or indeed if both occur. The research is further limited by being carried out in a range of settings and professional groups.

Interestingly, research focusing on problem and emotion-focused coping (Lazarus & Folkman, 1984) in dementia care staff was not identified in the current review. However, such a focus in future research might provide valuable information regarding cognitive coping processes in this group.

Physiological

The 'physiological' aspect of the BASIC Ph model is proposed to represent both positive and negative actions and practical ways of coping. Thus active coping, physical exercise, relaxation and avoidance are all considered to reflect a physiological response to adversity.

Of the identified articles, two were categorised as reflecting the 'physiological' element of the model. Both investigated the negative outcomes of stress in care staff. One related to the impact of conflict resolution style (Montoro-Rodriguez & Small, 2006) and the other to change in approach to care (Finnema et al., 2005).

Conflict resolution style. Conflict resolution styles have been associated with the morale, satisfaction and stress of care staff working in nursing facilities in the USA and Canada (Montoro-Rodriguez & Small, 2006). Confrontational conflict style was found to be a predictor of levels of depersonalisation (β=0.17) and emotional exhaustion (β=0.19) (Montoro-Rodriguez & Small, 2006). Avoidant conflict resolution style (β=0.18) and a

cooperative resolution style (β=-0.17) have also both been associated with depersonalisation (Montoro-Rodriguez & Small, 2006). It is important to note that the associations in this study were weak and that a cross-sectional design limited understanding of causality; that is to say that burnout may also negatively affect conflict resolution style. However, the findings highlight the impact of the active and practical ways in which staff work to resolve issues.

Change in care approach. Research has also investigated the impact of action-focused strategies such as adopting alternative approaches to work tasks. Emotion-oriented care aims to improve residents' emotional and social functioning and ultimately their quality of life. Finnema and colleagues (2005) adopted a longitudinal design to consider the effect of an integrated emotion-oriented care approach and randomised 146 care staff to either the intervention or 'care as usual' control group. Results found that staff who increased their use of emotion-oriented care skills reported significantly fewer stress reactions as measured by the GHQ-28 (Goldberg & Hillier, 1979). The characteristics of the residents were well described and, although not a focus of the current review, adopting emotion-oriented care was also found to have a positive effect in reducing residents' anxiety. Whilst adopting an emotion-oriented approach was considered as constituting a change in behaviour, reduced stress reactions might also reflect the benefits of a more 'invested' way of caring for residents; in this way, the results may also relate to the 'social' and 'affect' elements of the model.

Summary. The potential impact of ways of approaching conflict (Montoro-Rodriguez & Small, 2006) and care approach (Finnema et al., 2005) on psychological health in care staff has been highlighted. With only two studies within this section, the evidence is limited. However, the findings suggest possible benefits of exploring alternative action-focused coping strategies. To date, limited research has considered

alternative coping strategies, such as relaxation and physical exercise, and therefore may provide another area for future research.

Discussion

This review aimed to systematically identify literature relating to psychological health in dementia care staff and understand this literature in relation to the BASIC Ph model. A systematic search revealed an expanding evidence base regarding psychological outcomes in care staff. However, the search highlighted a focus to date on psychological morbidity rather than psychological health. Nevertheless, in highlighting factors associated with positive and negative outcomes, the review indicated possible ways in which the psychological health of care staff may be improved.

The BASIC Ph model provided a means by which factors associated with the psychological health of care staff could be readily categorised. This was evident from the concordance between the raters. This highlights the utility of the model not just as one detailing processes of coping and resiliency, as it is described, but rather as a comprehensive model of broadly defined psychological health that is able to meaningfully encompass much of the relevant literature.

Given the BASIC Ph model's epistemological focus on the individual, the categorisation of the literature to this model provides important insights into intrapsychic factors associated with psychological health in dementia care staff. However, the number of articles categorised as relating to the social element of the model highlight the impact of social factors on the psychological health of this group. A focus on intrapsychic may therefore limit the model's conceptualisation of systemic factors. As such, understanding of psychological health in this group may be enhanced by positioning the BASIC Ph

model within a broader contextual model which would allow for greater consideration of relational and systemic factors.

Fitting the factors associated with psychological health into the model required extrapolation and interpretation. Further, categorisation of the literature may have increased the risk of viewing the literature through a reductionistic lens. In spite of these potential caveats, the model arguably provides a coherent framework for future research and possible avenues for intervention.

Clinical Implications

In a review of interventions aimed at building resilience in care staff, Elliott and colleagues (2012) highlighted the need to better understand psychological health of dementia care staff. Interventions to date have largely focused upon education and instructional training (Elliott et al., 2012). However, viewing literature in terms of the BASIC Ph may provide a basis for planning more psychologically informed interventions. For instance, particular factors, such as social support, have been highlighted as impacting on psychological health and may therefore be enhanced.

The model may also present a basis for individual staff intervention that can be applied through an individual's reflection on, and exploration of, their own strategies (Lahad & Leykin, 2013). Broadening an individual's repertoire of the factors and processes highlighted would, according to the model, increase their flexibility in negotiating challenging situations (Lahad & Leykin, 2013).

In spite of the possible benefits of intervention, training may be compromised by the part-time and temporary nature of the workforce (Hussein et al., 2011). Whilst by introducing interventions aimed at increasing staff wellbeing it would be hoped that staff turnover would fall, training care home managers and generating a more fundamental

shift in the way in which staff are supported may provide a more sustainable means of promoting psychological health in care staff.

Research Implications

The majority of the studies reviewed were cross-sectional in design, thus limiting inferences about causality. Longitudinal research investigating psychological health in care staff is therefore an important area for future research. Additionally, though commonly used and well-validated, the measures employed focus on negative outcome, such as distress and burnout. In order to explore psychological health further, measures of wellbeing should be developed. Furthermore, research tended to consider outcomes across staff with varying levels of qualifications. Whilst it has been proposed that the staff groups caring for older people demonstrate more similarities than differences (Morgan, Semchuk, Stewart, & D'Arcy, 2002), future research may benefit from examining the factors associated with outcome in specific staff groups. This could be considered particularly pertinent given the association of level of education with work stress (Zimmerman et al., 2005) and burnout (Visser et al., 2008).

The research also originated from different countries, which may further limit the conclusions that can be drawn; however, such a critique may be countered by research detailing uniformity in findings across several countries (e.g. Edberg et al., 2008). Diversity was also evident in the range of organisations that the findings relate to. Such diversity when conducting research in this field has been highlighted as an issue in previous reviews (Manthorpe, 2014). Given the differing levels of emotional exhaustion identified between settings (van den Berg et al., 2006), studies included in the current review were required to relate to nursing home or equivalent settings. However, this was not to the exclusion of studies that examined multiple organisational contexts. Future research may benefit from focusing solely on the nursing home setting. Such exclusivity

may enhance characterisation of the workforce and aid researchers to determine specific nursing home-related factors associated with staff wellbeing, as well as facilitating future cross-study comparisons. However, given the limited literature to date, a more stringent approach does not yet appear possible.

It is important to note that whilst the findings highlight possible factors associated with outcome in care staff, a number of extraneous factors were also identified incidentally. Thus, for instance, the age of care staff (Brodaty et al., 2003; Duffy et al., 2009; Edvardsson et al., 2009; Testad et al., 2010; Zimmerman et al., 2005), their levels of education (Edvardsson et al., 2009; Visser et al., 2008), the length of time in their role (Åström et al., 1991; Saarnio et al., 2012; Zimmerman et al., 2005) as well as workload (van den Berg et al., 2006) and resident factors (Rodney, 2000), have all been associated with psychological health. As such, any future models need to incorporate these variables.

Limitations

The review was limited by a number of factors arising as a result of a comparatively small literature base in this area. Firstly, there was a relative lack of literature relating to positive outcome in care staff. Consequently, many of the conclusions are based on research detailing negative outcomes. Whilst psychological health has been associated with lower levels of negative outcome (Dackert, 2010) and has traditionally been measured as the absence of negative symptoms (Parker et al., 2003), a positive frame of reference would assert that psychological health is more than the absence of a disorder (Sheldon & King, 2001). The possible contention of this approach is therefore acknowledged. A review focused solely on wellbeing would be valuable. However, in light of the limited literature and difficulties in drawing research from a variety of disciplines, it would not have been sufficient here to consider factors associated

with psychological health alone. Furthermore, in order to amass adequate literature, publication dates spanned a number of years. In light of the changing nature of dementia care, up-to-date research is needed.

Literature relating to staff caring for older people was also generated from a variety of sources including social care, nursing, and psychology. Drawing on literature from a number of disciplines appeared to negatively affect the level of systematisation that it was possible to achieve with literature searching. The number of articles identified from hand searches completed consequent to the systematic search highlights this issue. There is an ongoing need to bridge literature generated from health and social care disciplines and for one to inform the other. However, consultation with two librarians highlighted that current resources do not appear to facilitate this.

Finally, the review may have been limited by the exclusion of non-peer-reviewed articles relating to care staff. Valuable information relating to the perspectives of this under-researched group may have been gained by including grey literature.

Conclusions

The literature relating to the psychological health of care staff is limited. Consequently, there was a lack of homogeneity across the participants and settings rendering cross-study comparison a challenge. Furthermore, outcomes were largely negative, relating to morbidity, even when discussed as positive. Nevertheless, the BASIC Ph model provided a means of conceptualising psychological health in this group. Whilst the model illuminated a number of factors impacting on psychological health, avenues for future research were also highlighted. Given the increased pressures on care staff, exploration of factors that enhance positive psychological health is an important area for further investigation.

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List of Appendices

Appendix A: Additional References for the BASIC PH Model

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Appendix B: Keyword Search Strategies

Key word search strategy for first search

(Resilien* OR Hardiness OR Coping OR Cope* OR "Psychological Endurance" OR "Psychological Health" OR Wellbeing OR "Well-being" OR "Staff Wellbeing" OR Stress OR "Occupational Stress" OR Burnout)

AND

("Care Staff" OR "Care Assistant*" OR "Care Worker*" OR "Healthcare Assistant*" OR Nurs* OR "Nursing staff")

AND

("Nursing Home" OR "Residential Home" OR "Residential Care" OR "Care home*" OR "Long term care")

AND

("Older Adult*" OR Elderly OR "Senior Citizen*" OR Aged OR Geriatric OR "elderly mentally infirm")

AND

(Dementia OR Alzheim* OR "Cognitive Impairment")

Key word search strategy for second search

(Resilien* OR Hardiness OR Coping OR Cope* OR "Psychological Endurance" OR "Psychological Health" OR Wellbeing OR "Well-being" OR "Staff Wellbeing" OR Stress OR "Occupational Stress" OR Burnout)

AND

("Care Staff" OR "Care Assistant*" OR "Care Worker*" OR "Healthcare Assistant*" OR Nurs* OR "Nursing staff")

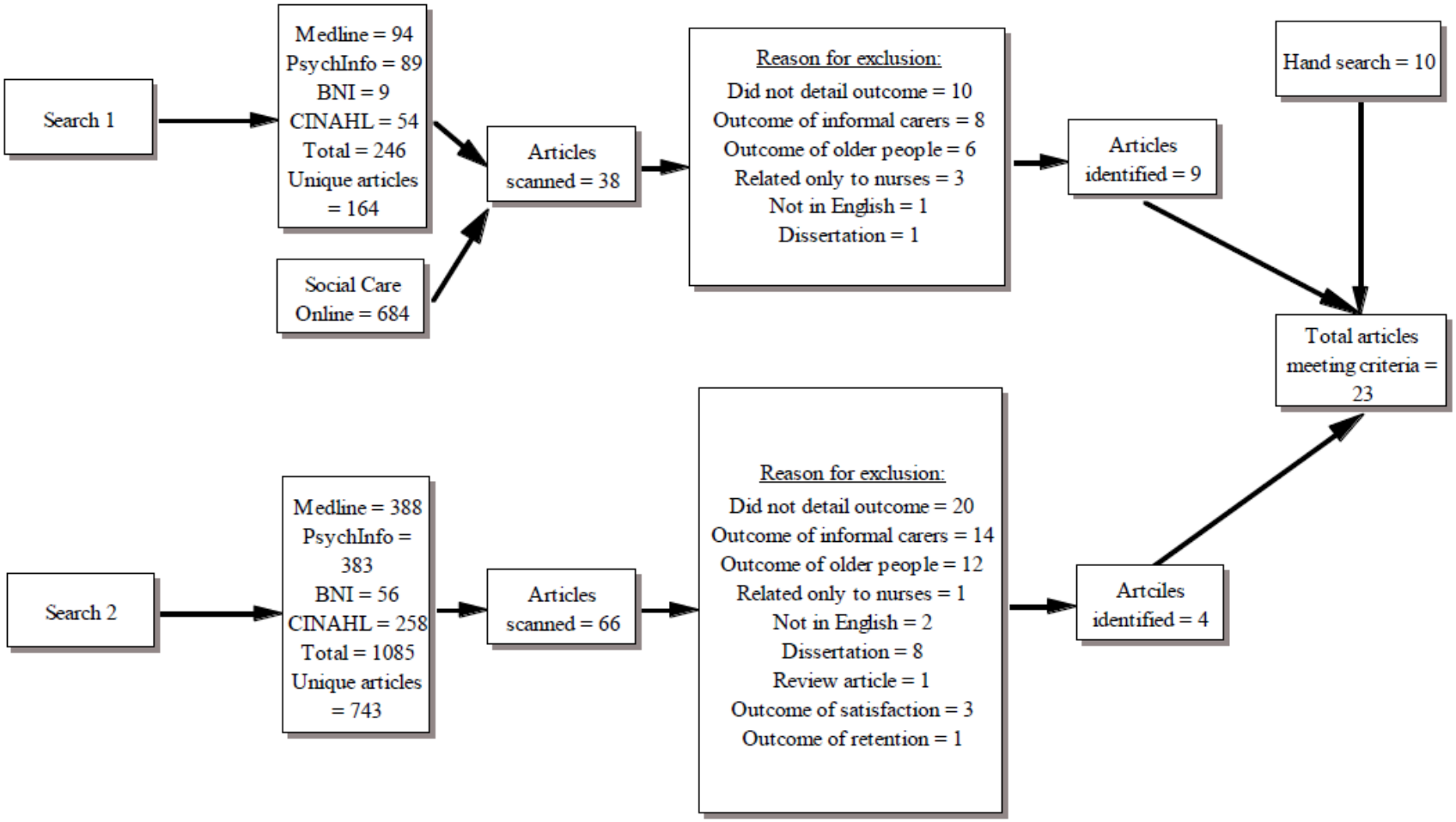
AND

("Nursing Home" OR "Residential Home" OR "Residential Care" OR "Care home*" OR "Long term care")

AND

("Older Adult*" OR Elderly OR "Senior Citizen*" OR Aged OR Geriatric OR "elderly mentally infirm")

Appendix C: Flow Chart Detailing Process of Search



Appendix D: Table of Study Characteristics and Key Findings

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Abrahamson, Suitor, & Pillemer (2009)	Nursing home (N=20) USA	N=655 (614 female)	Nursing assistant= 66.7% Licensed practical nurse= 18.8% Registered nurse= 14.4%	Cross-sectional survey design,	DV: Nursing Staff Burnout – 4 interview items; Staff Satisfaction – 4 interview items Family caregiving experience of staff (non-standardised Qs) Frequency of interpersonal conflict	<u>Structural Equation Modelling</u> Conflict sig association with burnout (+ve correlation, p <.001) Conflict sig association with satisfaction (-ve correlation, p <.001). Informal care experience associated with inc. conflict	S
Åström, S., Nilsson, M., Norberg, A., Sandman, P.-O., & Winblad, B. (1991)	Nursing home (N=1), Psychogeriatric clinic (N=1), Long-term care clinic (N=1) Sweden	N=60 (52 female) Age: M=40 (range=18-62)	Nurse aide= 22 Licensed nurse= 26 Registered nurse= 15	Cross sectional design with purposive sampling	DV: The Burnout Measure LaMonica's Empathy Construct Rating Scale Demographic interview	<u>Correlations with burnout:</u> - Attitudes (r=.50) - Empathy (r=-0.32) <u>Burnout variance explained</u> Experience of feedback at work & time spent at present place of work=28%.	A

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Barber, C. E., & Iwai, M. (1996).	Long-term care facilities USA	N=75 (56 female)	Nurse aides Nurses Social workers Primary care personnel	Cross-sectional survey design	DV: MBI (EE subscale) Role Conflict & Role Ambiguity Scale Workload & caregiving involvement (non-standardised Qs) Social support (2 x non-standardised Qs)	<u>Hierarchical regression EE (frequency) variance explained</u>: - Caregiver characteristics = 19% - Involvement = 5% - Work environment = 35% - Social support = 3% <u>Hierarchical regression EE (intensity) variance explained:</u> - Caregiver characteristics = 22 % - Involvement = 11% - Work environment = 32% - Social support = 3%	C*, S
Brodaty, H., Draper, B., & Low, L. (2003).	Nursing home (N=12) Australia	N=253 (205 female) Age: M=40.43 (SD=11.39)	Registered nurse= 77 Nurse's aide= 116 Enrolled nurse= 4 Diversional therapist= 4	Cross sectional survey design	DV: Swedish Strain in Nursing Care Assessment Scale (measures strain & attitude)	<u>Correlations with strain:</u> - Age (r=.165). - Experience (r=.213) - Attitude (r=-.440) (negative attitude – lower strain)	I*, C
Cole, Scott, & Skelton-Robinson (2010)	Nursing home for dementia (N=3), Continuing care ward (N=1), Nursing home (N=3) UK	N=96 Age: M=36 (range=17-59)	Care assistant= 70 Nurse= 26	Cross sectional survey design	DV: GHQ-28 Challenging Behaviour Scale Staff Support Questionnaire	<u>Nursing home (vs mental health) setting sig differences:</u> - Role ambiguity (greater in nursing home) - Support (greater in nursing home) <u>Correlation with psychological wellbeing:</u> - Perceived staff support ($r = 0.41$, $p < .001$)	S

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Duffy, B., Oyebode, J. R., & Allen, J. (2009).	Continuing care home (N=7) UK	N=61 (45 female) Age: M=42.6 (SD=14)	Care assistant= 38 Staff nurse= 19 Manager= 4	Cross-sectional survey design	DV: MBI Jeffcott Reciprocity Questionnaire Inventory of Geriatric Nursing Self-Efficacy	<u>Correlations with EE & variance explained:</u> - Self-Efficacy (r =-.53, p<.001; variance=28%). <u>Correlations with Dp & variance explained:</u> - Self-Efficacy (r =-.45, p<.001; variance=20%). <u>Correlations with PA & variance explained:</u> - Reciprocity with organisation (r =-.27, p<.05; shared variance 7%). - Self-Efficacy (r =.47, p<.001; variance=22%)	B*, S
Edvardsson, D., Sandman, P., & Nay, R. (2009).	Residential care unit (N=40) Sweden	N=344 (309 female) Age: M=42.6 (SD=12.1)	Registered nurse= 28 (div.1) Registered nurse= 194 (div.2) Personal care attendant= 122	Cross-sectional survey design	DV: Demand & Control Questionnaire (job strain) 100m visual analogue scales - Perceived unit caring climate - Knowledge of caring for people with dementia Possibility to discuss difficulties & ethical challenges; workplace-based education (non-standardised Qs)	<u>High job strain vs Low job strain sig. differences:</u> - education (p<.01) - perceived caring climate (p<.01) - work demand variables (<.001) - 3/6 work control variables (p<.001) <u>Job strain variance explained:</u> Caring climate, age, education, opportunity for discussion=19%	S

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Evers, W., Tomic, W., & Brouwers, A. (2001).	Nursing home (N=22) Netherlands	N=551 (516 female) Age: M=33.37 (SD=9.29)	Lower level= 38 Medium= 412 Advanced level= 101	Cross-sectional survey design	DV: MBI Self-Efficacy scale (adapted). Physical & psychological aggression (6 general items & 26 specific acts of aggression).	<u>Correlations with EE:</u> - Physical aggression (+ve correlation, p<.01) - Psychological aggression (+ve correlation, p<.01) <u>Correlations with Dp:</u> - Physical aggression (+ve correlation, p<.01) - Psychological aggression (+ve correlation, p<.01) <u>Correlations with PA:</u> - Self-Efficacy (+ve correlation, p<.01). <u>Hierarchical regression:</u> Psychological aggression predictor of EE & Dp Psychological aggression predicts more variance in EE than physical aggression. Self-Efficacy predictor of PA (p<.01).	B*, C

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Finnema, E., Droes, R., Ettema, T., Ooms, M., Ader, H., Ribbe, M., et al. (2005).	Psychogeriatric ward (N=16) in 14 nursing homes Netherlands	<u>Emotion-oriented care:</u> N=46 (40 female) Age: M=30.8 (SD=8.0) <u>Control grp (usual care):</u> N=53 (46 female) Mean age=30.2 (sd=7.4)	<u>Emotion-oriented care:</u> Nursing assistant= 40 Ward assistant= 1 Team Leader= 5 <u>Control grp (usual care):</u> Nursing assistant= 44 Nurse= 2 Ward assistant= 1 Team Leader= 6	Randomised clinical trial, Pretest-posttest with control grp	DV: The Organisation & Stress Scale; GHQ-28;	<u>Experimental vs control grp</u> - Experimental grp reporting emotion-oriented care showed less stress reactions than control grp reporting emotion-oriented care. <u>Correlations with stress</u> - Emotion-oriented care (-ve correlation)	Ph
Gruss, V., McCann, J. J., Edelman, P., & Farran, C. J. (2004).	Dementia care unit (N=2; 1 renovated, 1 traditional) USA	N= 27 (27 female) Age: M=44 (range=28-77)	Certified nursing assistant= 27	Cross sectional survey, between grp, design	DV: CSQ (modified to 19 items) Empowering organisational factors (presence/absence of 6 empowering factors) Rating of top 5 stressors	<u>Empowered vs non-empowered unit differences:</u> - Unit 1 more empowering factors (5/6) Nature of job stress: - Unit 1 (empowered) more resident-focused stressors (resident physical/mental wellbeing) - Unit 2 (non-empowered) more job-focused stressors (negative job characteristics)	S

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Heyns, P. M., Venter, J. H., Esterhuyse, K. G., Bam, R. H., & Odendaal, D. C. (2003).	State subsidised institution (N=21) South Africa	N=226 Age: M=38	Nurse= 50 Staff nurse= 5 Assistant nurse= 23 Care staff (no qualification)= 148	Cross-sectional survey design	DV: MBI SCS Fortitude questionnaire Biographical questionnaire	<u>Correlations with EE & variance explained:</u> - Sense of coherence (r=-.25; variance=3.86%) - Fortitude (r=-.23; variance=1.71%) - Demographic variables (variance=0.84%) <u>Correlations with Dp & variance explained:</u> - Sense of coherence (r=-.26; variance=7.23%) - Hours of work per week (variance=2.63% <u>Correlations with PA & variance explained:</u> - Sense of coherence (r=.27; variance=4.34%) - Fortitude (r=.23; variance=3.45%)	B
Juthberg, C., Eriksson, S., Norberg, A., & Sundin, K. (2008)	Nursing homes, Retirement homes, group housing, sheltered housing Sweden	N=146 (140 female) Age: M=45 (range=22-65)	Registered nurse= 50 Nursing assistant= 96	Cross sectional survey design	DV: MBI SCQ PCQ	<u>Correlations with burnout:</u> - Stress of conscience (r=0.66, p=0.001) - Perception of conscience (r=0.58, p=0.001)	
Moniz-Cook, E., Millington, D., & Silver, M. (1997)	Nursing home (N=2) UK	N=48 (45 female) Age: range=20-60	Care assistant=63% Experience M=6.9yrs (range=1mth-29yrs)	Cross sectional survey design	DV: GHQ-12; MBI WES Sheltered Care Environment Scale	<u>Correlations with EE:</u> - WES clarity (r=-0.61, p=0.01) <u>Correlations with Dp:</u> - WES task orientation (r=-0.58, p=0.01) - Work pressure (r=-0.61, p=0.01)	C

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009).	Nursing facilities, USA (N=5) Canada (N=2)	N=161 (primarily female) Age: M=40	Professional carers providing direct care (incl. varying roles).	Cross-sectional survey design	DV: MBI Staff morale: shortened version of psychiatric epidemiology research instrument Work demands (2x items re: n of residents & n of 'difficult-to-care-for' residents). Work resources (3xitems re: freq of care planning meetings; staff training & facility supplies Conflict resolution styles: organisational communication conflict instrument	<u>Correlations with EE:</u> - negative views re: residents ($p<.05$) - n of residents assigned ($p<.05$) - facility observed conflict ($p<.05$) - confrontational conflict resolution style ($p<.05$) <u>Correlations with Dp:</u> - avoidant conflict resolution style ($p<.05$) - confrontational conflict resolution style ($p<.05$). - cooperative conflict resolution style (negative correlated, $p<.05$). <u>Correlations with PA:</u> - intensive assigned residents ($p<.05$) - facility observed conflict (negatively correlated, $p<.05$). Conflict resolution styles also sig correlated with staff morale.	Ph*, C

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Rodney, V. (2000).	Nursing home (N=15) Australia	N=102	Registered nurses Primary care assistants Direct-care workers	Cross-sectional survey design	DV: Stress: Mood adjective checklist Rating scale for Aggressive Behaviour in the Elderly Personal Views Survey II Based on Dewe's (1987) coping methods: - Primary appraisal (4x items) - Secondary appraisal (3x items) - Coping strategies (58x item)	<u>High resident aggression (vs low aggression)</u> - Stress (sig higher with inc. aggression). <u>Correlation with stress & variance explained</u> - Primary appraisal (r=-.29, p<.01; variance=32%). - Secondary appraisal (r= -.21, p<.05; variance=<0%). <u>Correlations with hardiness</u> - Secondary appraisal (r= .22, p<.05). <u>Correlations with coping strategies:</u> - Secondary appraisal (r=.23, p<.01).	C

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Saarnio, R., Sarvimäki, A., Laukkala, H., & Isola, A. (2012).	Health centre ward, municipal & private nursing home, municipal & private dementia care unit (Total N = 45) Finland	N=350 (345female) Age: M=46 (range=18-66)	Registered nurse= 86 Practical nurse= 240 Other social & health care= 16 Outside social & health care= 6	Cross sectional survey design	SCQ (2x factors: 1) lack of inner strength; 2) external forces). Demographic variables & staff factors	Highest SCQ index scores: lack of time to provide the care a patient needs; work demands impact on time devoted to family <u>Associations with Stress of Conscience (SoC) - Lack of inner strength:</u> - Length of experience (Greater experience & increased SoC). - N of residents (More residents & increased SoC). - Type of employment (Permanent employment & increased SoC). <u>Correlations Stress of Conscience – External forces:</u> - Choice of work place (No other care work available & increased SoC). - N of children (2+ children & increased SoC).	C

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Schaefer, J. A., & Moos, R. H. (1996).	Nursing facility (N=13), Intermediate & residential care facility (N=1) USA	N= 405 (91% female) Age: M=42 (SD=11.7)	Registered nurse= 97 Licensed vocational nurse= 74 Nursing assistant= 179 Non-nursing staff= 55	Longitudinal (8mth f/u) survey design	DV: Job-related distress (2x 5-point Likert); Health & Daily Living Form (mood & physical symptoms) WSI WES	<u>Staff functioning at Time 1:</u> <u>Predictors of job-related distress:</u> - Supervisor relationship (p<.05) - Background variables (p<.001) - Work stressors (p<.001) <u>Predictors of depressed mood:</u> - Background variables (p<.001). - Work stressors (p<.001) <u>Staff functioning at Time 2:</u> <u>Predictors of job-related distress:</u> - Supervisor relationship (p<.001) - Background variables (p<.001) - Work stressors (p<.001) <u>Predictors of depressed mood:</u> - Background variables (p<.001). - Work stressors (p<.001) - Supervisor relationship (p<.001). Problems experienced with supervisors at Time 1 linked more depressed mood & physical symptoms at Time 2.	S
Schmidt, G., Dichter, N., Bartholomeyczik, S., & Hasselhorn, H. M. (2014).	Nursing home (N=50) Germany	N=305 (259 female) Age M=42.8 (SD=9.5)	Registered nurse= 204 Nursing aide= 101	Longitudinal survey design (2.5 yr period)	DV: COPSOQ (burnout subscale & general health item); WAI Satisfaction with the quality of care of residents with dementia	<u>Change in satisfaction over time</u> Satisfied →satisfied: Highest work ability, general health, lowest burnout (some decline over time) Dissatisfied → dissatisfied Deterioration in work ability, general health, burnout Satisfied → dissatisfied Pronounced deterioration in work ability, general health, burnout	A

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
te Boekhorst, S., Willemse, B., Depla, M. F., Eefsting, J. A., & Pot, A. M. (2008).	Group living home (N=19), Nursing home (N=7) Netherlands	<u>Nursing home staff</u> N=197 (186 female) Age: M=37 (range=35-40) <u>Group living home staff</u> N=183 (169 female) Age: M=43 (range=41-45)	<u>Nursing home staff</u> Nursing assistant= 6 Certified nursing assistant= 150 Registered nurse= 17 <u>Group living home staff</u> Nursing assistant= 18 Certified nursing assistant= 125 Registered nurse= 15	Cross sectional survey design	DV: MBI; Utrecht Burnout Scale Leiden Quality of Work Questionnaire	<u>Nursing vs group home sig. differences:</u> - Demands (higher) - Control (lower) - Social support (lower) - Burnout (higher) - Job satisfaction (lower) <u>Multilevel linear regression predictors of burnout:</u> - Work & time pressure (sig predictor of EE). - Decision authority (sig predictor of EE, Dp & PA). - Social support co-workers (sig predictor of EE, Dp & PA).	S

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Testad, I., Mikkelsen, A., Ballard, C., & Aarsland, D. (2010).	Dementia ward (N=13) in nursing home (N=4) Norway	N=197 (188 female) Age: M=43.1 (SD=12.9)	Nurse assistant= 23 Licensed practical nurse= 108 Registered nurse= 63 University degree= 3	Cross-sectional survey design	DV: PSS; HSCL-10; SHC QPSNordic	<u>Correlations with HSCL-10</u> - Control at work (-ve correlation, p<.004) - Mastery at work (-ve correlation, p<.008) <u>Correlations with PSS:</u> - Mastery at work (-ve correlation, p=.000) <u>PSS variance explained:</u> Care staff age, shiftwork & QPSNordic items - 25% <u>HSCL-10 variance explained:</u> Care staff age, shiftwork & QPSNordic items - 34.2% <u>SHC variance explained:</u> Care staff age, shiftwork & QPSNordic items - 28.6%	B

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
van den Berg, T. I., A Landeweerd, J., Tummers, G. E., & van Merode, G. G. (2006).	Nursing home (N=14), hospital (N=15) Netherlands	<u>Hospital staff</u> N=1204 (1019 female) Age: M=35.7 (SD=8.7) <u>Nursing home staff</u> N=1058 (963 female) Age: M=35.8 (SD=9.7)	<u>Hospital staff</u> Experience M=12.6yrs (SD=8.4) <u>Nursing home staff</u> Experience M=15.5yrs (SD=8.6)	Cross sectional survey design	DV: MBI (EE subscale) Workload (8 x items re: demands) The Organisation & Stress Scale (10 items re: Social support)	<u>MANOVA:</u> Nursing home staff sig greater levels of EE than hospital staff. <u>Multiple regression analysis predictors of burnout in nursing homes:</u> - Workload (r^2=.20, p<.001) - Social support (r^2=-.05, p<.001)	S

Author & year	Setting	Participants[a]	Job role/ level of training	Design	Measures[b]	Relevant findings	BASIC Ph[c]
Visser, S., Mccabe, M., Hudgson, C., Buchanan, G., Davison, T., & George, K. (2008).	Aged care facility (N=3) Australia	<u>Education + peer Support grp</u> N=17 (17 female) Age: M=46.82 (SD=10.97) <u>Control grp</u> N=25 (24 female) Age: M=44.52 (SD=9.94)	[not specified]	Pretest-posttest, 3 & 6 mth follow-up with control grp. Intervention: Education: 8wks, 2 per wk Education + peer support: Same with 4 wks peer support	DV: MBI Staff Attitudes Questionnaire (non-standardised)	<u>Education + peer support vs control grp</u> - Burnout (No sig difference) - Attitude re: skill & knowledge post intervention, 3 & 6mth follow up (Sig difference) - Attitude re: barriers to change at 3 & 6mth follow up (Sig difference)	S
Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., et al. (2005).	Residential care/assisted living (RC/AL) (N=31) & nursing home (N=10) USA	N=154 (144 female) Age: M=39.9 (SD=12.4)	Administrator= 11 Registered nurse= 1 Licensed nurse= 1 Certified nursing assistant= 136 Unknown= 5	Cross-sectional survey design	DV: WSI Approaches to Dementia Staff Experience Working with Demented Residents	<u>Correlations with WSI:</u> - Age (-ve correlation) - Time working with individuals with dementia (-ve correlation). - Satisfaction (-ve correlation) <u>Between grp-test:</u> Staff working 1-2yrs associated with: - Increased stress - Increased hope & person centred attitudes ($p<.01$)	B*, A

Note. [a]N indicates the total number of participants or settings. M = mean. SD = standard deviation. [b] DV = dependent variable. Outcome measures evaluating psychological variables and associated variables reported. MBI = Maslash Burnout Inventory (Maslach et al., 1996) consisting of EE (Emotional Exhaustion), Dp (Depersonalisation) & PA (Personal Accomplishment); SCS = Sense of Coherence Scale (Antonovsky, 1993); PSS = Perceived Stress Scale (Cohen et al., 1983); HSCL-10 = Hopkins Symptom Checklist (Strand et al., 2003); SHC = Subjective Health Complaints (Ihlebaek et al., 2002); QPSNordic = General Nordic Questionnaire (Elo et al., 2000); WSI = Work Stress Inventory (Schaefer & Moos, 1993); WAI = Work Ability Index (Tuomi et al., 1998); COPSOQ = Copenhagen Psychosocial Questionnaire (Nübling et al., 2005); CSQ = Caregiver Stress Questionnaire (Briones et al., 2002); WES = Work Environment Scale (Moos, 1994); GHQ = General Health Questionnaire (Goldberg & Williams, 1988); SCQ = Stress of Conscience Questionnaire (Glasberg et al., 2006); PCQ = Perceptions of Conscience Questionnaire (Dahlqvist et al., 2007). [c]B = beliefs & values. A = affect. S = social. I = imagination. C = cognitive. Ph = physiological. * Indicates primary BASIC Ph categorisation. References found in Appendix E.

Appendix E: References for Measures

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Appendix F: Table Illustrating Categorisation of Coping Processes

Layah & Leykin's (2013) categorisation of Skinner and colleagues' (2003) lower-order categories of coping to the BASIC Ph model

Belief (B)	Affect (A)	Social (S)	Imagination (I)	Cognition (C)	Physiology (Ph)
Optimistic action (can be Ph); Self-criticism (can be A and C); Religion; Praying; Seeking spiritual support (can also be S); Faith; Positive cognitive restructuring (can also be C); Positive reappraisal; Placing positive values on negative events; Acceptance; Resigned acceptance; Fatalism; Denial (also B-); Denial/minimisation; Positive thinking/focus on positive (also C); Helplessness (-) (maybe A); Give up; Criticise others; Seeking meaning (can happen through Ph);	Emotional approach; Aggression; Verbal aggression (can be C); Hostile action (-) (can be Ph); Irritable; Moody and acting out; Blame self (can be B and C); Emotional reaction – internalising; Feels difference and withdraws (can also be S-; Ph); Emotional expression; Emotion-focused aggression; Expressive; Internal; Worry (rumination) (can also be C); Anxiety amplification; Anxious anticipation; Fear self-statements; Fear of response; Fear of unlikely consequence;	Seeking social support; Seek and use social support; Seeking help/comfort (also A; C) from others; Support focus; Support mobilisation; Talking to others; Family communication; Antisocial action (-) (can be Ph); Social withdrawal (-); Self-isolation (-); Self-isolation (-); social support – emotional (also A); Social support – ventilating feelings (also A); Solace seeking (also A); Social support – instrumental (also C); Active support (also Ph; maybe B); Help/assistance	Distraction (can be C or B); Wishful thinking; Active wishing; Passive wishing; Escapist fantasy; Fantasy; Detaching self (can be A); Intrusive thoughts; Mental disengagement; Active forgetting (also C-); Imaginative; Imaginative transformation-sensation (also Ph); Imaginative transformation-context (also C); Pretending positive feelings (also Ph); Instinctive action (also Ph); Creativity*; Divergent thinking*.	Problem solving; Problem focused; Planful problem solving; Task oriented; Problem management; Primary control; Cognitive avoidance (-); Guidance; Cognitive refocus; Problem-focused aggression (can be A); Cognitive; Information seeking; Monitor; Question parents (also S); Understanding situation through communication with others (also S); Positive cognitive coping; Passive cognitive coping; Minimisation; Suppression of	Instrumental action; work and achieve (also C); Avoidant action; Work and achieve; Behavioural distraction; Direct action (can be C); Positive action (can be B); Active coping; Active behavioural; Rational action (can be C); Behavioural coping; Aggressive action (can be A); Behavioural escape; Evasion; Ineffective escapism (maybe B); Relaxation (rest); Passivity (-); Do nothing (-); Lack of coping/not coping; Substance use (alcohol/drug/sedation); Distancing (can be S-); Use of activity to

Belief (B)	Affect (A)	Social (S)	Imagination (I)	Cognition (C)	Physiology (Ph)
Making sense of the loss; Confrontive (maybe C); Growth; Drawing strength from adversity; Developing self-reliance and optimising; Developing confidence and optimism; self-improvement; Positive/ negative approach; Self-control (also C); Controlled reflectiveness; Resignation; Relinquished control; Restraint (also Ph-); Positive comparison; Coping self-statements; Compliance (also S); Distract/ignore; Ignore problems; Distraction/avoidance; Indecisiveness; Not worrying (also A)Perseverance (also	Emotion focused; Emotional processing; Emotional ventilation/discharge; Catharsis; Catastrophising (also B); Distress; Blame others (projection) (can be S); Emotional reaction – externalising; Humour; Emotion regulation; emotion regulating cognition (also C and B); Anger; Physical release of emotion (also Ph); Crying-emotion focused; Crying problem-focused (also C); Hiding feelings; Insinuating feelings; Emotional numbing (-); Isolation of affect; Direct emotion manipulation – tension reduction	seeking; Adult mediation; Seeking authority; Advice seeking (also C); Peer support; Social belonging; Assertive (maybe B); Direct discussion (maybe C); Adult-caregiver support (also A); Social entertainment; Social comparison; Accepting responsibility; Developing social support; Investing in close friends; Maintaining family integration; Cooperation; Maintaining social support; Parental support; Social action.		information; Blunting (maybe I/A); Cognitive restricting (can be B); Redefinition (can be B); Defensive reappraisal (can be A/B); Re-evaluation; Problem appraisal coping (can be B); Decision making; Logical analysis; Seeking understanding; Use of words to eradicate difference; Planning; Altering plans; Selective ignoring (also I); Negative affect (thinking) (also A-); Negotiation (compromise) (also A); cognitive self-control (also B); Behaviour regulating cognition (also Ph); Verbal intervention; Self-involve; Stop	camouflage difference; Use of actions to encapsulate difference; Disengagement (-); Behavioural disengagement; Assertive procedural vocalisations; Physical exercise; Professional help (including medical) (also C); Ignore pain sensation (also I); Substitution of rewards; Physical intervention; Palliative; Symptoms management; Inhibition of action (-); Suppressing feelings (-); Tension reduction; Increased activity; Engaging in demanding activity; Cautiousness (cautious action) (also C and B); Physiological arousal; Impulsive action; Self-destructive (maybe A); Help providing (maybe S);

Belief (B)	Affect (A)	Social (S)	Imagination (I)	Cognition (C)	Physiology (Ph)
C/Ph); Prepare for worst (also C); Reinterpret pain (also Ph); Self-calming (also A); Self-encouragement (also A); Stoicism; Endurance (also Ph); Destructive automatic thinking (also C); Deflecting from one's faults; Optimistic definition of situation; Self-esteem (also A); Naive optimism; Making amends (*also C/Ph); Optimistic appraisal and change; Non-punitiveness; Non-confrontation; Pestering; Reliance on discipline; Self-appraisal; Self-interest; Superstitious thinking	(also Ph); Accessing blame (responsibility) (also S and B); Emotional arousal (also Ph); Displacement; Loss of love (also S-)			and Think; Reality-oriented working through; Cognitive self-instruction; Uncertainty; Categorical thinking; Cognitive interference; Constructive automatic thinking; Draw on past experiences (also I); Dual focused; Non-procedure-related statements (-); Self-adaptation (also B); Stress recognition; Suppression (-) (if emotional then A-); Taking one step at a time; Thought stopping (-).	Non-procedure-related behaviours; Reactive behaviour; Self-initiated behaviour; Somatisation; Strive to rest and be alone (also S-); Suppression of competing activities.

Note. *Did not appear in Skinner et al., (2003); (-) reflects negative coping

Oxford Doctoral Course in Clinical Psychology

Understanding Experiences of Providing Dementia Care: Perspectives from Staff in the Care Home Context

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Understanding Experiences of Providing Dementia Care: Perspectives from Staff in the Care Home Context

Abstract

Perceived self-efficacy impacts on the psychological health of dementia care staff and their ability to provide care. The current study aimed to increase understanding of the experiences of self-efficacious care assistants. A qualitative study using purposeful sampling was conducted. Eight care assistants with high levels of self-efficacy participated. Interviews were analysed using interpretative phenomenological analysis. A contextual theme captured experiences of 'feeling torn' between competing demands when providing care. The second theme, 'togetherness and connection', included sub-themes of the need for support, closeness and the value of engaging. The third theme, 'attunement', described circularity of emotion, personal perspective-taking and empathy as guides to care. The final theme, 'caring as a part of life', described caring as part of assistants' identity, a genuine interest in people, an accepting attitude and motivation to care. The themes highlight important areas for further research and have implications for dementia care staff training.

Keywords: dementia, care assistant, care staff, self-efficacy

Proposed Journal: Dementia: The International Journal of Social Research and Practice

Introduction

Background

In 2014, it was estimated that 640,000 people were working in care homes (Skills for Care, 2014). The majority of these staff are care assistants and many have only basic training (Hussein, 2010). This has caused concern (Cavendish, 2013; Quince, 2013) and with an increased awareness of mistreatment (Biggs & Haapala, 2010) and reports of poor practice (Lloyd, Banerjee, Harrington, Jacobsen, & Szebehely, 2014), there is demand for more and better quality services for those with dementia (Department of Health, 2009). This demand is coupled with a projected increase in the number of people entering care homes with dementia (Laing & Buisson, 2007; Quince, 2013). Therefore, as well as managing the physical and emotional demands of the work, care assistants are under increasing pressure to provide good care to a growing number of older people, many of whom have complex needs. In addition to training, a number of personal factors, including self-efficacy, have been proposed to impact on the psychological health of dementia care staff. .

Self-Efficacy

Perceived self-efficacy can be defined as "the belief in one's capacities to organize and execute the courses of action required to produce given attainments" (Bandura, 1977, p. 3). In relation to elderly residential care, self-efficacy has been defined as "the beliefs or judgments of staff about those caring and nursing behaviours, skills and knowledge which are needed to provide safe, independent care for residents" (Evers, Tomic, & Brouwers, 2001, p. 442).

Low self-efficacy has been associated with burnout in dementia care staff (Duffy, Oyebode, & Allen, 2009; Evers et al., 2001). Theoretically, self-efficacy is thought to influence an individual's appraisal of a situation, whether coping behaviours

are initiated, how much effort is expended and how long effort is sustained in the face of aversive experiences (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). As such, levels of self-efficacy may therefore not only impact on the psychological health of dementia care staff but also on the coping behaviours they initiate in response to challenges within the care home context.

Low levels of self-efficacy are prevalent in care staff in the UK (Tadd et al., 2011). Given its association with psychological health and care provision, there is a need for research to consider how self-efficacy may be raised and supported among care staff (Duffy et al., 2009; Kokkonen, Cheston, Dallos, & Smart, 2014). Accordingly, it has been proposed as an area for intervention by the Promoting Excellence in All Care Homes (PEACH) study (Tadd et al., 2011). However, the beliefs, experiences and approaches of dementia care staff with high levels of self-efficacy in this context have not been considered and are a pertinent area for further research. Greater understanding of how efficacious care staff make sense of their experiences may highlight areas for intervention and further research.

Qualitative Approaches

Despite making up a significant proportion of the workforce in dementia care, little research has considered the experiences of dementia care assistants. The benefits of qualitative research in increasing understanding in under-researched areas have been expounded. Indeed, the few qualitative studies that have been conducted with care staff have been useful in elucidating barriers to care provision (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012), enhanced understanding of the impact of family members on care staff (Looman, Noelker, Schur, Whitlach, & Ejaz, 2002), the role of affective communication with residents (Carpiac-Claver & Levy-Storms, 2007) and psychological constructs, such as sense of coherence (Gustafsson & Strandberg, 2009).

Adopting a qualitative approach will therefore enhance understanding of self-efficacy in dementia care staff.

The aim of the current study was to explore the experiences of care assistants providing dementia care in care home settings. Adopting a qualitative methodology with a rigorous analysis will allow for an in-depth understanding of the lived experiences of dementia care assistants who perceive themselves to be highly self-efficacious in providing care. With greater insight into the experiences of those feeling competent in their work, avenues for future research and interventions that promote self-efficacy in dementia care staff will be highlighted; this in turn may positively impact on the psychological health of dementia care staff (Duffy et al., 2009; Zimmerman et al., 2005).

Interpretative Phenomenological Analysis (IPA) was chosen in light of its primary goal of "giving voice" and "making sense" of experiences (Larkin, Watts, & Clifton, 2006). IPA recommends a homogenous sample therefore only care assistants working in care homes were selected. This was felt particularly pertinent given the challenges they face and the current lack of research relating solely to care assistants.

Methods

Participants

Eight care staff who met the study criteria were included. Details of the participants are presented in the results section.

The inclusion criteria were:

1) Paid care worker employed in a care home registered to take individuals who have dementia.

2) Worked in this context for 6 months or more.

3) Mean score of six or more on the Inventory of Geriatric Nursing Self-Efficacy (Mackenzie & Peragine, 2003).

4) Fluent in English.

The exclusion criteria were:

1) A professional nursing qualification.

2) Participated in another research study in the last year.

3) Possible psychiatric disorder as indicated by scoring three or more on the General Health Questionnaire-12 (GHQ-12; Goldberg & Williams, 1988).

Procedure

Recruitment. The managers of care homes in Oxfordshire and Buckinghamshire registered to provide services for individuals with dementia, and who had expressed an interest in research studies, were sent a letter of invitation (Appendix G). Managers willing for their staff to be approached to undertake the research signed a management approval letter (Appendix H). Care staff within participating homes were offered a study pack which included a participant information sheet (Appendix I), a demographic data collection form (Appendix J) and a consent form (Appendix K), as well as a copy of the Inventory of Geriatric Nursing Self-Efficacy (Appendix L) and the GHQ-12.

As well as information from the participant information sheet, scores on the Inventory of Geriatric Nursing Self-Efficacy and the GHQ-12 were used to ascertain whether respondents met the criteria. The Inventory of Geriatric Nursing Self-Efficacy aims to quantify the extent to which staff perceive themselves able to manage common sources of caregiver stress. It consists of a 7-point Likert scale ranging from *"not at all*

confident" to *"very confident".* In light of the nature of the scale, and lack of normative data, a mean score of six was employed as a cut-off score; a mean score of six or more would suggest that an individual felt confident in managing common sources of stress (Mackenzie & Peragine, 2003). The GHQ-12 (Goldberg & Williams, 1988) was scored using the GHQ method (0-0-1-1) and, as such, scores of three or above indicated the presence of psychological distress. Further details of these measures can be found in Appendix L.

A letter was sent to each care home to thank participants for completing the study packs and to clarify the process of further contact from the researcher (Appendix M). Care staff who met the criteria were contacted by the researcher to arrange a time to conduct a semi-structured interview. Appendix N contains a more detailed account of the procedure.

Semi-structured interview. A semi-structured interview schedule was developed for the study (Appendix O). Construction was influenced by a review of the literature, supervisory discussion and the aims of the research. Appendix P provides a detailed account of how the semi-structured interview schedule was developed.

The interview allowed the researcher to pose questions pertinent to the study's research questions. However, in line with IPA philosophy (Smith, 2003), the schedule acted primarily as a guide and comprised open-ended questions which gave participants the opportunity to tell their story and talk about their experiences, focusing on areas that were important to them.

On the day of interview, confidentiality was reviewed, participants were provided with tangible examples of how their data would be used, and written consent to be interviewed was obtained (Appendix Q). Participants were reminded of their right

to withdraw. All interviews were conducted by the researcher on a one-to-one basis with participants in a private area at their place of work or at home. Interviews lasted between 30 and 60 minutes. Interviews were recorded on an encrypted Dictaphone and transcribed verbatim in order to maximise reliability. On completion, the researcher undertook post-interview reflection (Appendix R).

Data Analysis

All interview data were analysed using IPA (please refer to Appendix S for a background and rationale for choosing IPA). Initially, the semantic and key prosodic content were transcribed for each interview. In transcribing, the researcher tried to stay as close as possible to the actual words used by participants. All transcripts were anonymised and pseudonyms assigned. Reflections were written for each participant interview to document the researcher's reaction to these during the transcription. Each transcript was read several times to facilitate familiarisation with the content. Notes were taken to consider the flow of the interview and to acknowledge possible links to theory as well as assumptions and biases.

Subsequently, systematic coding was undertaken. Coding adhered to the two core principles of IPA – namely to understand the participants' world before developing an overtly more interpretative analysis (Larkin et al., 2006). As such, within each transcript, participants' objects of concern and experiential claims were identified. Interpretative comments were also made (as illustrated in Appendix T). These elements were collated to create a 'map' for each participant and emerging themes were generated (Appendix U). This process was completed for each participant.

Emerging themes were then compared across transcripts and themes were grouped together into clusters. These formed subordinate themes which were

subsequently grouped into superordinate themes. Quotes from each theme were reviewed to ensure that the themes generated were grounded in the data. The process of analysis within IPA is iterative; therefore themes were revisited and reconsidered throughout data analysis. The research supervisor had access to the interview transcripts to allow triangulation of the data. As part of the iterative process, the fit of themes as an accurate representation of the data was discussed with the research supervisor and ideas for emerging themes agreed upon.

The analysis of interviews in IPA relies upon interpretation of the participants' personal perception by the researcher (Larkin et al., 2006). The researcher's own beliefs and perceptions influence data analysis and ultimately the degree to which it is possible to enter an individual's personal world (Smith, Jarman, & Osborn, 1999). Reflection by the researcher on their own position, background, assumptions and beliefs and their impact on the data analysis is therefore key. The steps taken to increase reflexivity are detailed below and in Appendix R.

Quality Measures

Reflexivity. Several steps were taken to account of the researcher's own perspective and increase transparency regarding their position[10]. This allowed the researcher to consider their own perceptions regarding the participants' interpretations of their experiences. As such, a reflective diary was kept from the beginning of the research process to document the researcher's thoughts and feelings about the research and data (see Appendix R). A 'bracketing' interview was completed with a fellow IPA researcher prior to data collection in order to elicit the researcher's expectations and personal perspectives that might influence data collection and data analysis. Further,

[10] Whilst the researcher's voice could have been more active by using the first person and featuring more heavily in the main body of the paper, it was decided, in light of the importance of having a full and coherent depiction of the researcher's position, to have the majority of the reflexivity in the appendices.

detailed reflections were made following each interview and throughout the analysis phase.

Credibility checks. A number of procedures were employed to ensure the credibility and rigour of the findings. These included discussions with fellow IPA researchers, an expert in IPA and the research supervisor. Further, a systematic audit trail was kept throughout the process, from initial note-taking, to the marking of transcripts, to the development of emerging themes and the subsequent final structure. See Appendix V for a detailed account of the credibility procedures employed.

Ethical Approval

Ethical approval was granted by the University of Oxford ethics committee and the project was sponsored and indemnified by Oxford Health NHS Foundation Trust (Appendix W). Ethical implications, particularly those relating to the issues of consent, confidentiality, managing distress and risk, were considered (see Appendix X for detail).

Results

Situating the Sample

Of the 19 care staff who completed and returned the initial questionnaire pack, nine met the criteria for inclusion and eight responded consenting to interview[11]. All were care assistants, one of whom was a senior care assistant, one of whom also acted as a team leader and one of whom was also employed as an activity coordinator. See Table 1 for a summary of participants' characteristics.

[11] Of the 10 excluded, six had a mean self-efficacy score below six; three had a mean self-efficacy score below six and a GHQ-12 score above the cut-off; one had a mean self-efficacy score above six but a GHQ-12 score above the cut-off.

Compared to those who did not meet the criteria, there was a trend amongst the participants interviewed to have relatively higher levels of qualification and greater length of experience, as well as significantly higher levels of perceived self-efficacy (see Appendix Y for descriptive statistics of all respondents). Those interviewed were similar to the larger sample in terms of age and ethnicity.

Table 1

Participants' Characteristics

Participant	Age	Ethnicity	Time working as a professional caregiver
Jenny[12]	41	White British	>10 years
Gayani	52	Asian – Sri Lankan	1-2 years
Diwa	67	Asian/British – Filipino	>10 years
Jane	-	White British	6-10 years
Emma	25	White British	6-10 years
Carol	67	White British	>10 years
Pauline	52	White British	>10 years
Maria	42	Caribbean/British	>10 years

Overview of Themes

Accounts of experiencing dilemmas when caring for older people with dementia emerged within the care assistants'[13] narratives. This provided important contextual information and constituted the first superordinate theme. The second superordinate theme captured togetherness and connections in the care home and described the need for support from the care home community, closeness and the value of engaging with older people with dementia. The third superordinate theme encompassed attunement

[12] The names of all the care assistants, and any residents or colleagues mentioned in their narratives, were changed to ensure confidentiality.
[13] Participants will be referred to as care assistants throughout as this best describes their role.

between care assistants and residents; this was illustrated by the care assistants' descriptions of empathy, personal perspective-taking and circularity of emotion as guides to care. Descriptions of caring being part of life and linked to identity, having a genuine interest in people, motivation to care and an accepting attitude all emerged in the data and were captured in the final superordinate theme. See Table 2 for a summary of the themes.

Table 2

Extracted Superordinate and Subordinate Themes

Superordinate Themes	**Subordinate Themes**
Feeling Torn: *"Should I...take that decision?"*	-
Togetherness and Connection	The need for support from others: *"You don't want to feel alone"*
	Closeness: *"We are a little family"*
	The value of engaging: *"Their faces just beam"*
Attunement	Circularity of emotion: *"I'm happy 'cause they're happy"*
	Personal perspective-taking: *"We're the one who understand them"*
	Emotion as a guide to care: *"It is very, very emotional for me to see somebody suffering"*
Caring as Part of Life: *"This is more than a job"*	Caring is part of my identity: *"It is in my blood"*
	A genuine interest in others: *"They've all got amazing stories"*
	The motivation to care*: "It's like a drug and I get a kick out of it"*
	Acceptance: *"Every day is a new day"*

To illustrate themes, selected verbatim quotes are included within the text. Further illustrative quotes are presented in Appendix Z.

Feeling Torn: "Should I... take that decision?"

Feeling torn in what to do for the best emerged from different aspects of the care assistants' roles. The dominant tension reflected a desire to provide care in residents' best interests but potentially causing them distress in the short-term to achieve a longer term benefit:

> *So, which way do you go? It is abuse you can't force her, it's abuse. But if you leave her in a soiled pad, she's going to get sore, her bottom is going to breakdown, it is going to get, it's even worse abuse.* (Jane, 230)[14]

In relation to personal care, the words "abuse" and "force" were used by several of the care assistants alongside fear of causing harm.

Care assistants described how their own belief systems impacted on dilemmas. For instance, Carol described her feelings relating to a perceived need to feed people at the end of life: *"obviously you're not going to deprive them of food if they want to eat but to try and force food on somebody is, is not nice"* (273).

For some, over the years changing practice had exacerbated dilemmas. For instance, Diwa described difficulties administering medication and reflected that *"in the past, you had to put in jam or anything and they take it. Not now, if they don't like it, what can you do?"* (267). On reflection, differences were apparent between the perceived necessity of care tasks with personal care more likely to be viewed as a necessity compared to other care tasks, such as administering medication. Carers

[14] Corresponding line numbers relating to individual transcripts are given following each participant quote.

expressed powerlessness to provide some care in line with residents' needs and this was echoed in wanting to make change and speak out.

> *Oh I, I think I've made my feelings quite clear about that. I mean a lot of the other girls, the, the other girls don't like it either but they just sort of say "oh [the manager] knows". They don't like it but what can you do if you are told that she knows and she's happy to let it go on?* (Carol, 617)

The dilemmas extended beyond basic care and reflected complex conceptual challenges. Jane described the dilemma of responding to residents asking about loved ones who had passed away, explaining that *"although you can't tell them, you can't, you can't downright, blatantly lie"* (393); the dilemma and reluctance to *"tell them"* arose from wanting to protect residents from distress.

A perceived lack of experience or feeling ill-equipped also exacerbated dilemmas. Emma reflected on when she started as a carer and that *"if one person was calling you and somebody else was shouting or doing something and you, you found yourself, well, what do I do first?"* (169). Gayani, who lacked formal experience compared to the other care assistants, reiterated feeling *"doubtful sometimes"* about decision-making, wondering *"should I do that thing, should I, you know, take that decision?"* (411).

Tensions arose, not just from residents, but also from the competing needs and expectations of others. Three referred to relatives' power because *"ultimately what they say is what goes"* (Jane, 459). However, within their narratives differing priorities and expectations between residents' families and care assistants were highlighted. Colleagues' views or actions presented another direction in which the staff could "feel torn". Emma described trying to meet the multiple and conflicting demands placed upon

her as a result of working alongside an inexperienced care assistant; she explained that *"not only are you trying to do your job, keep the residents happy, you're also trying to explain everything you're doing and showing them"* (99).

Togetherness and Connection

All the care assistants described togetherness and connection within the care home. This was illustrated with descriptions of closeness, within which it was important to feel supported and connected.

The need for support from others: "You don't want to feel alone". All participants commented on the importance of feeling supported. Four mentioned the support gained from sharing problems. This was a means of managing stress because *"you don't have to pile any worry or stress on yourself… you can just off-load it to somebody and then have help with it"* (Emma, 130).

Carol echoed *"you have to, you've got to, you've got to let it out"* (600); however, in contrast to other narratives of seeking support within the care home, this was in the context of sharing problems with her husband and daughter. Whilst insistent that you have *"got"* to let stresses out, it was apparent for Carol and others that sharing problems at work was not always possible. Maria explained that *"the nurses listen... but they're so busy as well. They've got their own things going on, looking after residents"* (618). Thus, whilst the value of sharing problems and seeking support was dominant, the reluctance of burdening colleagues was also evident.

The positive support gained from being part of *"a team working along together"* (Jenny, 86) was described by six care assistants. Further, the necessity for a *"very strong team to deal with this illness"* (Diwa, 575), was highlighted by the impact of colleagues on care assistants' experiences; indeed, *"it totally depends who you are*

working with whether you have a good shift or not. Totally, totally" (Carol, 420). The experience of work being contingent on their colleagues illustrates the inter-dependency and importance of the staff team.

Closeness: "We are a little family". Six care assistants spoke about their affection for, and attachment to, residents. Care assistants described becoming *"attached with them, even though, you know, they talk to you not nicely, or they hit you or whatever"* (Diwa, 592). *"You just can't help it, you're, you're only human"* reflected Emma (766). There is an inevitability and unconditionality to the attachment. Maria's parallel with the *"bond"* with residents being *"like having a child"* (234) elucidates this. However, attachment to residents also presented a challenge for some, particularly *"when you see them helpless, looking helpless in the bed"* (Maria, 557). There was a concern about getting *"a bit too close"* (Maria, 219) and a need to maintain some distance in order to protect oneself from the distress of when residents died. Emma explained *"I've numbed up to, um, getting that attached and not letting it emotionally drain you 'cause it did before. It was awful."* (767).

Six care assistants described the care home as *"a family"*; as Pauline reflected, *"We spend more time in our work environment than we do at home. So, we should be one big family"* (217). Closeness was echoed in narratives of caring for residents as if for family as well as descriptions of residents' attachment needs and attachment between residents. Narratives described a sense of pleasure from this closeness. The account of two care assistants returning to the care homes having previously retired highlighted this.

The value of engaging: "Their faces just beam". Seven care assistants described wanting to connect with residents. Wanting to engage residents was mirrored

by experiencing distress when witnessing residents' isolation. As such, interaction was viewed by four as a fundamental marker for knowing they were doing a "proper" job. Pauline reflected, *"Even if it's for like, for two minutes with each resident you know you've done your job when you do that"* (518).

Care assistants' accounts highlighted the meaning and reward gained even from small interactions. Maria reflected this when speaking about a resident, George:

> *I says to him "good morning George". He'll look up, he, he's bed-ridden, and he'll look up and he'll look and he'll say "morning". But just that difference, just to say 'morning', that interaction, it, it, it's really great.* (168)

However, the lack of a verbal response was not seen as a barrier to connection, rather attention was paid to more subtle signs of engagement. It was noted that whilst *"they can't communicate with you… their faces will light up if you talk about a certain subject"* (Jenny, 226). The reward from small signs was reiterated when staff noticed a resident's *"eyes sparkle"* (Jane, 763) or *"a lovely little smile"* (Maria, 414).

The experience of interacting provided reciprocal rewards as well as a means of regulating emotion. Jenny reflected that *"you relax more if you are having a nice conversation with someone"* (332). Several care assistants also described their enjoyment in sharing humour with residents; for two this was particularly dominant in their narratives. Pauline explained *"We all sit there and we all have a laugh with the residents and it's just, my god, it's just, priceless."* (235)

Attunement

Within all the narratives were accounts of personal perspective-taking and empathy as guides to care. Further, seven care assistants described their own happiness arising from residents' happiness.

Circularity of emotion: "I'm happy 'cause they're happy". Seven care assistants spoke about the happiness or sense of satisfaction they gained from witnessing residents' contentment:

> *I am always happy, being happy, every day I do something good. Every day, I make, make some people happy. Every day I make some people comfortable. Then it gives me a big pleasure.* (Gayani, 189)

Circularity of emotion between care assistants and residents was reiterated by descriptions of how residents' distress gave rise to their own feelings of distress; as Maria explained, *"He gets quite distressed, it's quite distressing when you hear him"* (88).

A sense of satisfaction gained from knowing that residents were content was also present:

> *As long as I can go home knowing that each of them have had a relatively good day and I've left them and they're happy and they're comfortable and content, then I'll be, that's me, that's fine, I'm done.* (Emma, 721)

Emotion as a guide to care: "It is very, very emotional for me to see somebody suffering". Seven care assistants described the use of emotion to guide their care. Gayani reflected the differences between the technical knowledge of senior staff and the emotional understanding that care assistants draw upon: *"We can see them and I can, emotionally we can, you know what they want like that"* (394).

Empathy with residents' emotions as well as those of colleagues was also described as guiding decision-making. The power of emotion felt by residents when learning of the death of a loved one led to Jane holding back from telling them:

> *This lady's breaking her heart because her husband's dead. She might then forget that she's been told that and wonder, but for those four or five minutes, she's terribly distraught. Then you think why say that to her and then walk out, walk out and leave it to us to sit with our arms around her while she cries, you know... I mean I wouldn't want to cause her that pain.* (409)

Within two narratives, the particular importance of end of life care was dominant and guided by compassion:

> *Even their end of life care, I just, want to be in the room with them until you know, 'til the, the end you know. Give them that support, the care, you know, whatever they need.* (Maria, 224)

Personal perspective-taking: "We're the one who understand them". Within all narratives were descriptions of perspective-taking to guide care. For instance, considering whether *"if that was your mum, would you do that? Or your dad, would you do that?"* (Carol, 224) facilitated decisions about what was best for residents. Relatedly, care assistants used perspective-taking to make sense of residents' aggression. Jane reflected:

> *You've got to remember, from the age of two or three they would never have messed themselves or soiled themselves, they would never have done it so when they do do it, even if they've got a pad on, they get cross, they get cross with themselves and they take it out on you and the amount of times I've been slapped and hit and punched.* (221)

Jane's awareness of the meaning of incontinence for residents provided an empathic explanation for their distress and behaviour. Compassion for residents' experiences was

evident, even during challenging situations. During these potential times of fear it was apparent that care assistants' own feelings were secondary to consideration of the perspectives, and distress, of the person for whom they were caring.

Accounts of challenging behaviour were present across all the narratives. Five care assistants described that, at these times, residents *"don't know what they are doing"* (Diwa, 776), for all the behaviour was attributed to their illness or underlying causes rather than something residents did *"deliberately"* (Gayani, 303). As Emma reflected, *"It helps that you know that they have Alzheimer's or dementia... in the back of your mind it's like, they don't know they've done it"* (415). The belief in a lack of intent therefore has a protective function.

However, lack of intent contrasted with descriptions in all narratives of the effect of the care assistants' approach on residents and their role in triggering challenging behaviour. This resulted in some questioning whether it was *"something that I said or physically did that he didn't like and all of a sudden he's just whacked you one"* (Emma, 420). All care assistants spoke about the impact of their communication on residents; as Jenny pointed out, *"if you shout at them, they will carry on shouting"* (285). Further, some felt the behaviour of residents was contingent upon the degree to which staff could adopt residents' perspectives; as Diwa explained, *"He punches carers because they don't understand him"* (137).

At times of resident distress, four described wanting *"to sit down and know how you can help them"* (Maria, 393). As well as a desire to gain residents' perspectives, there were accounts attempting to understand *"why's this come about?"* (Jenny, 316); the desire to act in accordance with *"what they wish"* (Jenny, 166) prompted this. For three care assistants, it was apparent that such an understanding of residents increased

confidence; Diwa reflected, "*I have no fear because I know how to deal with him, I know what he wants"* (474).

Caring as Part of Life: "This is more than a job"

Care work being more than a job for participants was illustrated through descriptions of innate abilities, a genuine interest in others, an attitude of acceptance and motivation to care. Within accounts was the perception that some people do care work *"just to earn money"* (Diwa, 286) but that more than this is needed:

> *You can always get a caring job. You look in the paper any day of the week, care assistant, care assistant, care assistant, every, every day, and I think sometimes people go into this, "Oh, I can't get another job, I'll go and be a care assistant, it's a job, you know, I'll do it, it's a job" and it's not, they are not doing it because they want to do it... they are not thinking about what they are doing.* (Carol, 786)

Caring is part of my identity: "It is in my blood". All the care assistants related caring to their identity. Seven described inherent abilities to care. For Emma, caring was in her *"blood"* (7), *"second nature"* (139) and something she had a *"knack"* (572) for.

Echoing the concept of inherent ability, was the statement that caring is intuitive and training not necessary *"if you have a good conscience"* (Gayani, 99); on reflection, this was in contrast to her later view, echoed by a further five care assistants, that knowledge is empowering. Four care assistants, who had been working in the role for a number of years, described that they *"just used common sense"* (Diwa, 77) prior to receiving training, thus reiterating the use of intuition providing care.

Care assistants spoke about having their own, internal, standards and views of what was "good" or "bad". Carol described, *"I always, always thought... if you think something is wrong, your conscience thinks it's wrong, then it probably is wrong, isn't it?"* (628). For Gayani, internal standards were informed by religious belief: *"I am a Buddhist. I always think if, if you do something good or if you do something bad or we hurt people that, it, it's always in my mind."* (186)

As well as themes of inherent qualities, caring was described as shaping care assistants' identities. For instance, two reflected on the influence of caring for a family member. Gayani's experience of caring for her mother gave her *"a very big concern about elderly people"* (16) which led her into her current role. Carol reflected on the experience of her parents entering care homes and the empathy this gave her for the experiences of relatives:

> *It's not nice, it was horrible… and it's difficult for relatives when they have to put them in somewhere like this and the guilt thing and some people don't cope well with visiting and they don't understand why they don't recognise them and, so, it's really hard.* (229)

Relatedly, three care assistants described how life experiences and age had equipped them for care. There was a recognition that *"getting older is not easy"* (Diwa, 381) and that their own ageing increased empathy for the challenges faced by residents. Carol reflected that *"when you are 18, 20 you are never going to be 60, 70, 80"* (151) and that her own ageing, and experiencing the *"whole gambit of caring"* (215) for children and grandchildren, had equipped her for her role.

Four described the experience of providing formal care as formative. Emma described that caring for older people with dementia *"makes you have a different*

perspective on life" (605). Two care assistants spoke about the particular influence of a manager on their identity. Pauline reflected *"I can honestly say today, if it wasn't for him, I probably wouldn't be how I am"* (248).

Genuine interest in others: "They've all got amazing stories". Four care assistants explicitly mentioned their interest in people, as Jenny described: *"It is nice to know different things that they used to do that you can chat with them about"* (232). For some, this interest extended outside the care home:

> *When I do see older people outside of work, I, I know, I'd just love to know their, or help them, or talk to them but, the fact that I am a stranger always sort of like, yeah, you don't do that.* (Emma, 554)

A genuine interest in people was illustrated in the anecdotes of individual residents, which were present in all narratives. This genuine interest was also reflected by five care assistants who highlighted the need to think about individual residents in the context of their lived experience to date:

> *Some of them are amazing, you hear their stories when they are able to tell you their stories, when you, when you read what their families have written about them. You can tell by the twinkle in an eye or the rude laughter what they were like, even if they are hitting you when they are laughing.* (Jane, 847)

The motivation to care: "It's like a drug and I get a kick out of it". The notion of caring being like a drug was illustrated by participants' investment in, and need to, care. All care assistants spoke about being invested in their work and reflected that this was a necessity because caring is an *"all or nothing"* (Carol, 445) job. Care assistants' investment was evident in the illustrations of going *"that extra step for the*

residents" (Maria, 221). Narratives not only described investment in residents but also in the community of the care home. For instance, Pauline spoke about her current place of work as being *"institutionalised a bit"* (190) and how *"because of the environment, it makes you want to stay and give your all and just give more and more and more"* (469). Her investment in, and desire to improve, the home was highlighted by her repetition of *"more"*.

Caring was also described as a duty. Thus, care assistants reflected that they *"must help them"* (Gayani, 19) and that *"no one is going to look after them, it is us"* (Diwa, 408). On reflection, both Gayani and Diwa had moved to the UK as adults and so may have differing cultural views regarding care. Indeed, Gayani explained about her culture: *"we look after our parents on our own, at home. Er, we don't put them into care homes like that"* (10).

The motivation to care was mirrored by all describing *"a big reward"* (Pauline, 375) or sense of satisfaction gained from doing *"the job properly"* (Diwa, 409). Pauline reflected *"I can walk out that door with my head up and pat myself on the back 'cause I feel and I know, I've done a good job"* (227). The reward from caring did not seem to decrease over time and a number of participants reflected on their enduring *"love"* of the job: *"I love my job... I still enjoy it as much now as I did when I first came"* (Jenny, 193).

Acceptance: "Every day is a new day". Within seven narratives was the presence of an accepting attitude. This was reflected on by some as becoming *"used"* to the inevitable physical challenges of aggression and emotional challenges when a resident dies. Pauline described, *"I've got no fear because over the years, I've been battered, kicked and punched and, so I'm used to that environment"* (123).

However, care assistants' accounts moved beyond just becoming *"used"* to challenges. The need to *"just work with what you have got"* (Emma, 726) and *"go with the flow"* (Carol, 348) illustrated an accepting attitude. Reflecting on a difficult day, Emma noted:

> *It doesn't feel great but then I know that if I am in the next day it could be a completely different day and so, I try not to dwell on, not so very nice shifts 'cause it could be a brilliant day the next day.* (736)

Discussion

Four superordinate themes related to feeling torn by competing demands, togetherness, attunement and caring as relating to identity. Seven care assistants contributed to the theme of feeling torn. All care assistants contributed to the remaining three superordinate themes.

Feeling Torn: "Should I...take that decision?"

Care assistants' narratives supported the proposition that ethical issues and moral dilemmas are evident across dementia care (Hughes & Baldwin, 2006). The theme also resonates with research describing care staff experiences of moral ambivalence and being exhausted by competing demands (Stenbock-Hult & Sarvimäki, 2011) as well as findings that an inability to meet residents' wishes and residents' non-compliant behaviour make care staff's work more difficult (Goergen, 2001). As such, the theme may reflect the theoretical concept of stress of conscience, which relates to the shortcomings and contradictory demands experienced by nurses caring for older people (Juthberg, Eriksson, Norberg, & Sundin, 2007, 2008). It is possible to consider whether care assistants' acknowledgment and reflection on difficult decisions, and the

uncertainty and insecurity associated with these (Stenbock-Hult & Sarvimäki, 2011), may contribute to their sense of efficacy in deciding what to do.

Togetherness and Connection

The results revealed a need for support and the importance of being part of a team. For some, difficulties within the team were a primary source of stress. These accounts contrast with suggestions that residents are a primary source of stress for nursing home staff (Goergen, 2001). However, concordant with the present narratives is the identified relief from stress gained from talking with colleagues (Goergen, 2001). The importance of team relations resonates with findings that the perceived team climate has a significant positive correlation with wellbeing, and a significant negative correlation with stress reactions, in nurses (Dackert, 2010).

Within the theme of togetherness and connection were concepts of attachment and the care home being akin to a family. These narratives resonate with the finding that 92% of professionals, working in a skilled nursing facility, reported surrogate family bonds with residents (Sumaya-Smith, 1995). The attachments the group described having with residents may link to previously identified associations between secure attachment styles, higher levels of self-efficacy and lower levels of burnout (Kokkonen et al., 2014). In this way, one could wonder whether this highly efficacious group may also have more secure attachments.

Detaching from residents was also present in the care assistants' narratives and presented a means of self-protection. This is in line with nurses' descriptions of protecting themselves by dissociating from the people they were caring for as well as their own feelings (Stenbock-Hult & Sarvimäki, 2011). In support, detachment has been associated with lower levels of strain (Brodaty, Draper, & Low, 2003). However, the

seemingly contradictory narratives of attachment and detachment were striking and present an area that requires further understanding.

The value and importance of interaction also emerged within the data. The association between staff-resident interaction and resident wellbeing has long been recognised (Nussbaum, 1991). However, the value and reward that care assistants gain from such interaction is, as far as the author is aware, less well described. That said, this finding is perhaps not unsurprising given that emotionally meaningful social interaction constitutes a basic human need that impacts on wellbeing (Carpiac-Claver & Levy-Storms, 2007) and effective, or positive, contact with aged care residents has been associated with job satisfaction (Moyle, Skinner, Rowe, & Gork, 2003).

Attunement

The theme of attunement encompassed the concept of circularity of emotion between staff and residents. Nurses' experiences of distress arising from witnessing older people's distress has been reported in prior qualitative research (Stenbock-Hult & Sarvimäki, 2011). However, the striking accounts of a positive emotional state of care assistants by virtue of residents' positive emotions have not, to the author's knowledge, been previously described in the literature. Nevertheless, the narratives resonated with readings of Buber's (1970) philosophical "I and Thou" stance, which describes a relationship defined by mutuality and reciprocity.

Related to circularity, was the use of emotion as a guide to care. Interestingly it has been suggested that nurses who are emotionally open and sensitive may be more easily hurt (Stenbock-Hult & Sarvimäki, 2011) and that staff with high levels of empathy are at risk of developing burnout due to deeper involvement (Maslach & Jackson, 1982). Conversely, the current findings are in line with research associating

higher empathy with reduced risk of developing burnout (Åström, Nilsson, Norberg, Sandman, & Winblad, 1991); the current group illustrated high levels of empathy and emotional involvement but indicated feeling competent and having low levels of psychological distress.

Emotional involvement has not only been associated with staff wellbeing but also care provision. In this way, genuine concern and engagement have been found to encourage empathic understanding (Hughes & Baldwin, 2006). By contrast, the failure of residents' problems to touch care staff emotionally has been associated with increased incidents of inappropriate restraint (Goergen, 2001). Further research may benefit from considering the impact of the emotional connection and empathic understanding between care staff and residents on care provision.

The broad theme of attunement also encompassed narratives of personal perspective-taking. Perspective-taking has been proposed as a way of understanding the wants and relationships of others and that, in order to act in residents' best interests, one must consider the perspectives of many (Hughes & Baldwin, 2006). The care assistants' narratives of perspective-taking also resonate with the concept of "consequentialism", namely that in order to know whether an action is right or wrong, you look at the consequences of doing or not doing it (Hughes & Baldwin, 2006).

The subordinate theme encompassed perspective-taking as a means of understanding why resident's behaviour had arisen as well as a perceived lack of intent in residents' behaviour. Findings that nursing home staff cope with stress by adopting the view that residents are not responsible for their behaviour (Goergen, 2001) are in line with the present findings and a potential area for further exploration.

Caring as Part of Life: "This is more than a job"

"Caring as part of life" reflected investment in care and encompassed subordinate themes of caring relating to identity, a genuine interest in others, acceptance and motivation to care.

In relation to identity and the concept of an internal guide to facilitating care provision, care assistants' accounts supported the postulation that conscience acts as a guide for right and wrong in dementia care (Hughes & Baldwin, 2006). Interestingly, four care assistants had past experience of informal care and this was described as shaping their identity as carers. The impact of caring informally on the experience of providing formal care has been noted (Coogle, Head, & Parham, 2006). In contrast to the current themes, it has been suggested that personal experience as a family caregiver may promote a more critical view of the relatives of older people with dementia (Abrahamson, Suitor, & Pillemer, 2009). However, the impact of having experience of providing informal care appears to be complex. For instance, nursing assistants with experience of caring for a friend or relative with Alzheimer's disease have been reported both to have higher levels of intrinsic job satisfaction as well as lower levels of career resilience compared to those with no informal care-giving experience (Coogle et al., 2006).

Overall, the group had slightly more experience than the larger sample. Age as well as experience was described, by the majority, as equipping the care assistants for their roles. The experiences of this group may therefore reflect the increased self-confidence through maturation and development described by nurses caring for older people (Stenbock-Hult & Sarvimäki, 2011). In this way, the meaning care assistants make of their work may change with time and experience. For instance, it has been

found that nurses' own vulnerability is viewed as moving from weakness to strength with increased age, experience and maturity (Stenbock-Hult & Sarvimäki, 2011).

The accepting attitude described by care assistants, particularly in relation to aggression, has been echoed in qualitative research (Robinson & Cubit, 2007). Interestingly, an accepting attitude is purported to result in mentors neglecting to prepare nursing students for challenges in dementia care, which increases their experiences of not knowing how to respond (Robinson & Cubit, 2007). This highlights the need for more experienced dementia care staff to prepare and support new staff entering the care assistant role.

The theme of a genuine interest in others was dominant and resonated with Brooker's (2003) model of person-centred care. This model emphasises valuing people with dementia, treating people as individuals and looking at the world from their perspective. On reflection, it was striking that whilst these elements recurred throughout the narratives, the commonly used term 'person-centred care' featured only once; thus, rather than solely constituting a phrase, the experiences and attitudes of this group resonated with the underlying principles of this approach.

Taken together, the superordinate themes of connectedness, perspective-taking and conscience have evident parallels with the broader theme of ethical sensitivity (Weaver, 2007). Empathy and perspective-taking, intuition and connectedness, benevolence, genuineness, commitment, awareness of effects of actions, values and conscience are among the 36 characteristics of ethical sensitivity described by Weaver (2007). Ethical sensitivity may enhance feelings of competence in managing dilemmas and may, by extension, underlie what it is to be highly self-efficacious in this context. Furthermore, attributes of empathy, conscience, values and commitment are likely to

impact on the care individuals provide. Echoing the National Health Service drive to recruit the right people, it could be suggested that recruitment for dementia care staff should also attend to employing "the right staff with the right skills" (National Quality Board, 2013 p. 3), such as ethical sensitivity, rather than focusing on staffing ratios.

Methodological Reflections

The selected sample could be considered limited. The participants were all interviewed on the basis of high perceived self-efficacy. The voices of those with lower levels of self-efficacy, who may be struggling in this context, were therefore not heard. However, adopting a positive frame of reference is important for enlightening intervention given that psychological health is more than the identification of problems (Sheldon & King, 2001). Indeed, it has been highlighted that where the reality of care is insensitive to staff's needs, and places unreasonable expectations and demands on them, we should not ask why some carers fail to care but rather why most do not (Beckett, 2013). It was hoped that by considering individuals with high levels of self-efficacy, increased understanding of this group could be gained, in turn highlighting areas for future research and intervention.

Although demographically reflective of dementia care assistants in the UK, the sample may also have been limited by all care assistants being female. Differences have been noted between male and female morality and ethics. Women are purported to value caring, responsibility and interrelationships and men rights, autonomy and justice (Gilligan, 1995). Descriptions of female ethics resonate with the identified themes. As such, gender differences may impact on the experience of dementia care assistants. Further research with male care assistants is therefore needed.

Whilst the aim of IPA is not to generalise, the sample was ethnically diverse and reflective of the UK dementia workforce, of whom 81% are White British (Hussein, 2010). On reflection, cultural differences between two participants may have had an impact on experience and values related to care. Further research may benefit from exploring the experiences of those from different cultures who work in this field, particularly in light of possible ongoing processes of acculturation.

Six of the care assistants had completed National Vocational Qualifications (NVQ) Level 3, which confers eligibility for senior care assistant work. The National Minimum Standards for Care Homes for Older People (Department of Health 2003) prescribe that a minimum of 50% of care assistants in any given care home should have NVQ Level 2. However, as of March 2009, 10-15% of care homes had not met this criterion (Eborall, Fenton, & Woodrow, 2010). As such, the current group were more than averagely qualified. It is possible to reflect on the benefits of completing relevant training and the possible contribution that increased declarative knowledge made to the sense of efficacy in this sample.

With regard to data analysis, the study benefited from a detailed reflective journal which provided a coherent and rich account of the researcher's position throughout the research process. Furthermore, a number of credibility checks enhanced the rigour of the research. These included extensive discussions with fellow IPA researchers, the research supervisor and an IPA expert. However, further steps could have been taken, such as gaining feedback from dementia care assistants regarding the interview schedule and the themes generated.

Relevance to Clinical Practice

With more people with dementia entering care homes, Clinical Psychologists may be increasingly called upon to provide staff interventions and training. The current findings have important implications for contributing to such pressures. For instance, the results highlight the value of support. Interventions aimed at enhancing the team climate in particular have been proposed as a means of increasing staff self-actualisation, in turn augmenting their ability to deal with stress (Dackert, 2010).

Further, the results may point to the possible utility of reflective groups. The implementation of such groups may be particularly pertinent in relation to challenging situations. Indeed, it has been noted that nurse aides, whilst having to manage complex psychosocial issues, are least trained in affective aspects of care (Carpiac-Claver & Levy-Storms, 2007). Reflective groups may therefore increase confidence and competence in these aspects of care. Such groups may also provide a forum for promoting thought relating to dilemmas and encouraging increased perspective-taking. Given the relation between the current results and characteristics of ethical sensitivity (Weaver, 2007), enhancing ethical sensitivity through training and reflection may also be an important means of increasing confidence, competence and ultimately wellbeing in this group. In turn, this would result in more effective care for older people with dementia.

Finally, given the largely positive experience of care assistants in the current data, increasing self-efficacy amongst dementia care staff may also provide a further area of intervention; for instance, by providing training relating to common sources of stress, such as dilemmas in care. Enhancing self-efficacy has already been suggested as an area of intervention that may improve the emotional well-being of care staff (Duffy et al., 2009; Tadd et al., 2011). Further, given the postulation that self-efficacy is a

significant predictor of behaviour (Bandura, 1977), enhancing self-efficacy may also impact on the care that staff provide.

Conclusion

The importance of considering how perceived self-efficacy can be raised and supported among dementia care staff has been highlighted (Duffy et al., 2009). In order to do so, it is necessary to understand what it is to be self-efficacious in this context. This study explored the experiences of dementia care assistants with high levels of perceived self-efficacy working in a dementia care home.

The dilemmas described by staff were striking. As well as highlighting the challenges and dilemmas faced by highly self-efficacious dementia care assistants, the findings illustrated the use of support, attunement and the intrinsic abilities they have in order to manage these. Whilst some concepts, such as the importance of social support, have been reflected in previous research, accounts of the rewards gained from caring for older people with dementia, and the impact caring has on identity, have not been so comprehensively reported. These themes highlight areas for further research and interventions aimed at improving the wellbeing of staff..

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List of Appendices

Appendix G: Letter of Invitation to Managers

Alice Coates, Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology,
Isis Education Centre,
Warneford Hospital,
Oxford,
OX3 7JX

Email: alice.coates@hmc.ox.ac.uk
Tel: [redacted]

Address
Date

Dear Manager's name,

We are writing to invite staff from your care home to take part in a research study looking at the experiences of care staff of older people who have dementia. There has been little research that has explored how the thoughts and feelings of care staff influence their practice. This research aims to gain a better understanding of paid care staff's experiences and the positive ways they approach their work. In doing so, we hope that we can then share the learning with care homes to improve care practice and staff support both in participating homes and more widely.

The study will involve staff completing some short questionnaires and the researcher speaking with a small number of staff who are willing to take part in an interview. The study is being completed as part of a doctoral qualification in clinical psychology by Alice Coates, Trainee Clinical Psychologist and will be supervised by Dr Jane Fossey, Associate Director of Psychological Services. The study is sponsored and indemnified by Oxford Health NHS Foundation Trust.

We would be grateful if you would consider your staff taking part in the study. Alice Coates will be phoning to discuss this and provide further information.

If you would prefer not to be called about the study please let us know within one week of receiving this letter. If you have any questions please do not hesitate to contact me at alice.coates@hmc.ox.ac.uk or on 07841918449.

Thank you for your time in considering this.

Yours sincerely,

Alice Coates
Trainee Clinical Psychologist

Appendix H: Management Approval Letter

Alice Coates, Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital
Oxford,
OX3 7JX

Email: alice.coates@hmc.ox.ac.uk
Tel: [redacted]

Address
Date

Dear Manager's name,

Re: Exploring care staff experiences (ECSE)

Thank you for discussing the research project with me. Below is a summary of your agreement for your staff to be approached.

☐You agreed that I could approach members of your staff about our research.

☐You agreed/didn't agree that the research interviews that may take place with some of your staff can be conducted at [Name of care home].

We would be grateful if you could confirm your consent to the above by signing in the relevant space overleaf.

If you have any questions please do not hesitate to contact me at alice.coates@hmc.ox.ac.uk or on 07841918449

Please find enclosed study packs for you to circulate to staff.

Many thanks again for letting us work with your staff team.

Yours sincerely,

Alice Coates
Trainee Clinical Psychologist

Signed:

Manager name	Date	Signature

Researcher name	Date	Signature

Appendix I: Participant Information Sheet

Exploring care staff experiences (ECSE)

Information sheet for Care Professionals

Invitation to take part in a research study

We would like to invite you to take part in a research study. Before deciding whether or not you would like to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully. Please feel free to ask if there is anything that is not clear, or if you would like more information.

What is the study about?

We are interested in learning about the experiences of care staff working with older adults with dementia. We are inviting staff to participate in an interview with a researcher. We would like to hear about your professional experiences of caring for older people with dementia, your views of the work you do as well as your views of yourself as a carer.

Caring for older people with dementia can present a challenge. Research has suggested that carers of older people with dementia can be vulnerable to emotional exhaustion. Emotional exhaustion has been found to impact on the care that staff are able to provide. However, many staff do not experience difficulties as a result of caring and continue to provide good care despite the challenging work they undertake. Little research has explored the thoughts and feelings of care staff in this situation. The current study aims to better understand the experiences of care staff who feel that they are effective in their caring role.

We feel that it is extremely important to increase understanding of the experiences of care staff of people with dementia and the ways in which you continue to provide good care despite the challenges you face. We also hope that this will allow us to have a better understanding of the needs of staff and how care staff are able to do their work. This will potentially lead to an improvement in care for people with dementia.

Who can take part in the study?

We are inviting you to participate as you work within a care home in Oxfordshire or Buckinghamshire. We are interested in hearing the experiences of paid care staff who have cared for older people with dementia for 6 months or more. We are looking to

obtain personal accounts and perspectives of paid care assistants who **do not** have a professional qualification (e.g. are not a registered nurse). Care staff who cannot speak fluent English will not be able to participate in the study due to a lack of funding for an interpreter.

Do I have to take part?

We would like to invite you to take part in these research interviews, but whether or not you do so is entirely up to you. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason, up until two weeks after the interview. If you withdraw, within two weeks after the interview your data will be removed from our database. However, after this time your data will have been analysed and it will no longer be possible to remove this from our database, but please rest assured that this data will not be able to identify you. If you withdraw from the study there will be no penalty; your future participation in other projects will not be affected by this decision and any information that you have provided will be destroyed confidentially if you wish it to be.

What will happen if I take part?

If you choose to take part you will be asked to complete some brief questionnaires about yourself and your current role as well as a consent form. This should take approximately 15-20 minutes. You can do this in your own time and return it to the researcher. If you do not complete and return the consent form when you return the questionnaires, we will assume that you are giving implied consent for this information to be included in this study. Once returned to the researcher, the information will be stored securely and the information will be anonymised.

Some people who return questionnaires will then be invited to meet the researcher – Alice Coates – to take part in an interview about their role and experiences. Not everyone who returns the questionnaires will be invited to have an interview, the decision about this will be based on the answers you have provided to some of the questions. However, having information about your experiences from the questionnaires you fill in still provides valuable information for this project.

If you are invited to meet the researcher, you will be interviewed separately on one occasion by Alice Coates. The interview will take place in a private area at your place of work or a venue of your choosing. It is important that the interview is private and confidential. If you choose to meet for the interview at your place of work, we will contact your place of work to ensure that there is a suitable private place for the interviews to take place. It is expected that the interviews will last between 1 and 1½ hours.

The interview will involve talking about your professional experiences of caring for older people with dementia, your views of the work you do as well as your views of yourself as a carer. This is not a test and there are no right or wrong answers. We simply want to better understand your experiences of the work you do.

We would like to record the discussion so that we do not miss anything important. However, it is important for you to be assured that all information will be treated confidentially and all data will be anonymised.

Will the information I provide be kept confidential?

Yes, all of the interviews will be recorded on an audio recorder and saved in an encrypted folder and typed up onto a password protected computer. Any information we receive about you from the interviews or questionnaires will have your name and address removed and will be stored separately so that you cannot be recognised from it. All other data will be stored in a locked cabinet at the Fulbrook Centre. The researcher and their supervisor, Dr Jane Fossey, will have access to this data. Your data will be kept for a maximum of two years after the project is complete.

What you say in the interviews will be kept confidential. However, if during the interview it appears that you or another individual is at high risk of serious harm, confidentiality may be breached in order to protect the person. In this situation, this would be discussed thoroughly with you before any action was taken.

For the write up of this study direct quotes from the interviews will be used. You will be asked just after the interview if there is anything that you said that you don't want to be used. All quotes will be anonymised and what we talk about in the interview is confidential.

What are the potential benefits of taking part?

The interviews will be a chance for you to tell us what you think of your work. This will be extremely valuable in helping us to understand the experiences of care staff which may impact on services and the way training for staff who provide care for older people with dementia is developed in the future. It has also been reported that people have found it beneficial to share their experiences and felt as though they were helping others by sharing their experiences.

What are the possible disadvantages and risks of taking part?

There are limited disadvantages to taking part and no risks. It is possible that some people may find it upsetting to discuss their experiences. There will be time set aside at the end of the interview to discuss how you are feeling, if you wish to discuss it.

What will happen to the results of the study?

The study will be written up as part of a doctoral degree in clinical psychology. The results may be presented at meetings and will also be written up the study for publication in an academic journal. No individual will be identified in any publication or meeting. On the day of the interview you will be asked if you wish to be sent a summary of the findings.

What if there is a problem?

If you have a concern about any aspect of this study, please speak to Dr Jane Fossey (01865 738445) who will do her best to answer your query. The research should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Who is doing this study?

Alice Coates, Trainee Clinical Psychologist, is carrying out this study as part of a doctoral degree in clinical psychology. The project is supervised by Dr Jane Fossey. The study is sponsored and indemnified by Oxford Health NHS Foundation Trust and it has been reviewed by, and received ethics clearance through, the University of Oxford Central University Ethics Committee, CUREC (ref: MSD-IDREC-C1-2014-134).

What do I do now?

Thank you for taking the time to consider the study and for reading this information. If you decide to participate in the study then please return the consent form and questionnaires as soon as possible. When Alice Coates receives the consent form and questionnaires she may then be in contact to arrange a convenient time to hold the interviews.

Who do I contact for information or advice?

If you would like further information please feel free to contact Alice Coates, Trainee Clinical Psychologist:
Alice.coates@hmc.ox.ac.uk
[redacted]

Thank you for considering whether you would like to take part in this research study.

Appendix J: Demographic Information Form

Exploring care staff experiences (ECSE)

Demographic data collection form

It would be helpful if you could answer all of the following questions. However if there are any questions you do not want to answer please leave them blank.

Name: _____

Date of birth: _____

Are you:

☐ male ☐ female

What is your job title? _____

Do you work:

☐ full time ☐ part time

Other (please specify): _____

How long have you worked at this care home?

☐ less than 6 months ☐ less than 1year ☐ 1-2 years
☐ 3-5 years ☐ 6-10 years ☐ over 10 years

How long have you worked as a professional carer?

☐ less than 6 months ☐ less than 1year ☐ 1-2 years
☐ 3-5 years ☐ 6-10 years ☐ over 10 years

What other jobs have you worked in?

_____
_____

Have you had personal experience of caring for someone with dementia (for example a friend or a member of your family)

☐ Yes ☐ No

If yes, what is/ was your relationship to them ?

_____

How long have/did you provide support to them ?

_____

Have you completed any of the following qualifications (tick as many as apply)?

☐ NVQ level 2 ☐ NVQ level 3 ☐NVQ level 4
☐ QCF level 1 ☐ QCF level 2 ☐QCF level 3 ☐QCF level 5
☐ Other college qualification ☐ Undergraduate university degree ☐ Postgraduate university degree
☐ School/college qualification (e.g. GSCE, A-Level) or equivalent outside of the UK
Please state**.....**
☐ None of the above

Have you completed any additional QCF awards/certificates? (for example, award in awareness of dementia or dementia care certificate)

☐ Yes ☐ No

If yes, please provide details

_____
_____

How would you describe your ethnicity? (Choose one option that best describes your ethnic group or background)

☐ White/British ☐ White other
☐ Asian ☐ Asian/British
☐ Black/African/Caribbean ☐Black/African/Caribbean/British
☐Mixed/multiple ethnic background ☐Other ethnic group
Please state: Please state:

What is your first language? _____

Are you fluent in English?

☐ Yes ☐ No

Thank you for taking the time to answer to complete this questionnaire.

Appendix K: Consent Form 1

Alice Coates, Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology,
Isis Education Centre,
Warneford Hospital,
Oxford,
OX3 7JX

Email: alice.coates@hmc.ox.ac.uk
Tel: **07841918449**

Exploring care staff experiences (ECSE)

Consent form for Care Professionals

We are interested in learning about the experiences of care staff working with older adults with dementia. Initially, we are asking staff to complete some brief questionnaires. Some people who return questionnaires will then be invited to meet the researcher to take part in an interview about their role and experiences.

Participant Identification Number: _ _ _ _ _ _ _ _ _ _ _ _

Please tick the box

1. I confirm that I have read and understood the information sheet for care professionals (dated 10/02/2015). I have had the opportunity to consider the information, ask questions and have received satisfactory answers to my questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without penalty or having to give a reason for withdrawing. ☐

3. I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. ☐

4. I understand who will have access to the personal data provided, how the data will be stored and what will happen to the data at the end of the project. ☐

5. I understand that the research will be written up as a student's thesis and understand how personal data used in the thesis will be published and stored. ☐

6. I understand how to raise a concern and make a complaint. ☐

7. I agree to take part in this study and am happy to be contacted by Alice Coates, Trainee Clinical Psychologist. ☐

My preferred mode of contact is:

		Details (with best time to contact)
Telephone	☐	.....
Mobile	☐	.....
E-mail	☐	.....

Name	Date	Signature
Researcher	Date	Signature

Appendix L: Details of Measures

Characteristics of the GHQ-12

The General Health Questionnaire-12 (Goldberg & Williams, 1988) is a widely used short screening instrument comprised of 12 items. Goldberg and colleagues (1997) found the GHQ-12 to have good overall sensitivity (83.4%) and specificity (76.3%). The mean area under the ROC curves was 0.88 with a narrow range. Goldberg and colleagues (1997) scored the scales using both the GHQ method (0-0-1-1) as well as using a Likert method (0-1-2-3). It was found, for the GHQ-12, that the GHQ method was better for specificity and sensitivity than the Likert method. The GHQ-12's validity characteristics were not significantly different when accounting for gender, age group or educational level.

Characteristics of Inventory of Geriatric Nursing Self-Efficacy

The Inventory of Geriatric Nursing Self-Efficacy is a 9-item measure specifically developed for individuals providing nursing care to geriatric populations to quantify the extent to which individuals perceive themselves able to manage common sources of caregiver stress (Mackenzie & Peragine, 2003). The scale is internally consistent (Cronbach's $\alpha = 0.96$; average item-total correlation .83). Temporal consistency, ascertained by comparing scores taken at 3 time points, was found to be significant. Although test-retest reliability was not significant from pre to post-intervention ($r=.37$, $p>.05$) it was significant from post-intervention to 3 month follow-up ($r=.56$, $p<.05$).

Copy of the inventory.

Appendix: Inventory of Geriatric Nursing Self-Efficacy

Instructions: For each of the following situations, how confident are you that you could remain calm, resolve the problem, and achieve a positive outcome? (Please circle the appropriate number)

1. You are extremely busy, you are behind in your work, and one of the residents is following you around and trying to grab your arm.

Not at all confident 1 2 3 4 5 6 7 Very confident

2. The husband of a newly admitted resident constantly instructs you on how to care for his wife. It seems that nothing you do is good enough for him.

Not at all confident 1 2 3 4 5 6 7 Very confident

3. A nurse on your shift approaches you at the nursing station and demands to know why you are working so slowly.

Not at all confident 1 2 3 4 5 6 7 Very confident

4. One of the residents often swears and curses at other residents and staff. While you are helping him with his wheelchair, he curses and nearly kicks you.

Not at all confident 1 2 3 4 5 6 7 Very confident

5. You are at the nursing station and you see a resident's daughter walking briskly towards you. She looks very upset and angry.

Not at all confident 1 2 3 4 5 6 7 Very confident

6. A colleague of yours is avoiding you for some reason. This is making your job difficult because you work closely with him.

Not at all confident 1 2 3 4 5 6 7 Very confident

7. Every time you see one of the residents, she asks: "When do I get to go home?" This has been going on for months.

Not at all confident 1 2 3 4 5 6 7 Very confident

8. The son of one of the residents corners you, blames you for ignoring his mother, and demands that you spend more time looking after her.

Not at all confident 1 2 3 4 5 6 7 Very confident

9. A colleague of yours is constantly comparing herself to you, insisting that the residents and their families prefer the care she provides to your care.

Not at all confident 1 2 3 4 5 6 7 Very confident

References

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Appendix M: Letter of Thanks for Participants

Alice Coates, Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital
Oxford,
OX3 7JX

Email: alice.coates@hmc.ox.ac.uk
Tel: **07841918449**

Address

Date

Exploring care staff experiences (ECSE)

Dear Team,

Thank you so much to those of you who took the time to fill in and return the questionnaires for my research.

As you know, I also wanted to speak to a few people to find out more about your experiences but I am not able to speak with everybody. If you have sent back your questionnaires and have not heard from me within 3 weeks of sending them I will not be making contact with you to arrange a follow up interview. However, the information you have already provided will help me to be able to better understand the perspectives of people who provide dementia care.

Thank you again for taking the time to fill out the questionnaires and for your support with this research.

I will be sending a summary of my findings in nine months when I have completed the project.

Yours sincerely,

Alice Coates
Trainee Clinical Psychologist

Appendix N: Step-by-step Account of Procedure

1. Care homes in Oxfordshire and Buckinghamshire registered to provide services to people with dementia were identified by the researcher and the research supervisor. Care homes that had not taken part in research recently were approached in order to reduce burden.

2. A letter of invitation was sent to the managers of the identified care homes. Initially six homes were approached. This was extended to 16 in order to meet recruitment need. A follow-up call was made by the researcher to address any questions and to ascertain if the care home managers would be happy for their staff to be approached about the research.

3. Those managers who agreed their staff could be approached, were then sent a letter to sign to indicate management approval. Seven care homes provided management approval.

4. Study packs, which included a participant information sheet, demographic information form, consent form, General Health Questionnaire-12 (GHQ-12; Goldberg & Williams, 1988) and Inventory of Geriatric Nursing Self-Efficacy (Mackenzie & Peragine, 2003) questionnaires were circulated to staff.

5. Staff who were willing to take part in the study were asked to complete and return the GHQ-12 (Goldberg & Williams, 1988), Inventory of Geriatric Nursing Self-Efficacy (Mackenzie & Peragine, 2003), demographic information and consent forms.

6. A letter was sent to care homes to thank participants for completing the study packs.

7. The returned forms were reviewed by the researcher. On the basis of their responses, individuals who met the inclusion and exclusion criteria were contacted by the researcher to confirm their willingness to participate in an interview. At this time, information about what participation would include was reviewed and potential participants were encouraged to ask questions.

8. The researcher arranged a time to conduct a 1:1 interview with each of the participants. If participants wanted to be interviewed at their place of work, the researcher offered to contact the care home and book a private room in the care home in which to conduct the interview.

9. At the time of the interview, the process of the interview and the limits of confidentiality were outlined; the issue of privacy was discussed in a tangible way. For instance, participants were given an example of how their data might appear. The researcher clarified their role. That is to say that it was explicitly stated that the researcher would be listening to people's experiences rather than addressing any difficulties identified or exploring change.

10. Participants were requested to provide written consent to be interviewed.
11. The researcher used the semi-structured interview schedule as a guide for the interview. Each interview lasted between 30 and 60 minutes.
12. Following termination of the interview, an informal discussion and reflection on the process of participation took place between the researcher and the participant.
13. Participants were provided with an opportunity to withdraw their consent at this stage.
14. Participants were asked whether or not they would like to receive a summary of the research findings.
15. On returning to the researcher's base, the audio data was uploaded onto a secure server and was password protected. The original paperwork was stored in a locked cabinet.
16. Following each interview, the researcher completed a post-interview reflection.
17. Where possible the interview that had been completed was transcribed the same day. During transcription, names were preceded by a special character (#) in order to identify them easily. Directly after transcription, personal names were replaced with pseudonyms.
18. A unique code was given to each participant in order to label paperwork, original questionnaires and audio data; this anonymisation was logged in order to keep track of this process.
19. Data analysis was completed by the researcher.
20. The research was written up for dissemination and appropriately tailored feedback was written for participants.
21. On completing the research the data was archived; all data was labelled as confidential, with name and contact details of researcher attached.

References

Goldberg D., & Williams P. (1988). *GHQ a Users Guide to the General Health Questionnaire.* Windsor: NFER-NELSON

Mackenzie, C. S., & Peragine, G. (2003). Measuring and enhancing self-efficacy among professional caregivers of individuals with dementia. *American Journal of Alzheimer's Disease and other Dementias, 18,* 291-299. doi: 10.1177/153331750301800507

Appendix O: Semi-structured Interview Schedule

Semi-structured interview guide

1) **What brought you into doing this job?**

Prompts:

- *Can you tell me the story of how you got here? When did you start working with older people/people with dementia? Why did you start working here?*

2) **If you were showing a new member of staff round, how would you describe your job?**

Prompts:

- *What does your job involve? What is your role?*

3) **Can you tell me about your experience of caring for people with dementia?**

Prompts:

- *What is it like working with the clients? Their relatives? Other staff?*
- *How do you feel about this?*

Questions exploring the factors that make the job easier/harder to do

4) **What things make it easier to do your job?**

Prompt:

- *Personal things? Staff factors? Organisational factors?*

5) **What things make it more difficult to do your job?**

Prompts:

- *Personal things? Staff factors? Organisational factors?*

Questions exploring identity as a carer and beliefs about work

I have asked you some questions about your job. I would also be really interested to hear more about how you cope with your work, the way that you feel about yourself as a carer and the things that you think are important to being a carer.

6) **How do you feel about yourself as a carer?**

Prompts:

- *What kind of carer are you?*
- *What are your thoughts and feelings about your job?*
- *What are your thoughts and feelings about the people you work with?*
- *What keeps you working here?*
- *How do you see your future as a carer?*

7) **What qualities do you think you have that help you to do your job?**

Prompts:

- *What skills/strengths help you do your work well?*
- *How do you deal with problems?*
- *How do you cope with difficult thoughts and feelings that might come up?*
- *Can you tell me about a time when you experienced a challenging situation? What did you do, think, say?*
- *When things are more difficult, are there particular things that you do? or say?(exploring use of beliefs, affect, social, imagination, cognition and physiological coping responses)*

8) **What is it like when things go well in your job?**

Prompts:

- *What are the good bits?*
- *What are the benefits/pleasures of this work?*
- *What are the bits that you enjoy?*
- *When things are going well, are there particular things that you do? or say?*

9) **Are there qualities that you see in other members of staff that you wish you had? How would those qualities help?**

Prompts:

- *Who do you think does well at their job? Why?*
- *What things do they do or say that you think makes them good at their job?*

Is there anything else about <u>your</u> own skills, personality or style in your work in a care home for people with dementia that you would like to add?

<u>Debrief</u>

Is there anything that you might not have thought about before that occurred to you during the interview? Is there anything else you think I should know in order to understand your experience better? Is there anything that you would like to ask me?

Appendix P: Development of the Semi-structured Interview Schedule

The semi-structured schedule provides a set of questions that guide the interview but do not dictate it. Thus whilst the researcher has an area of interest, the aim is to gain as much information about the participant's psychological and social world as possible (Smith & Osborn, 2003). As such, open ended and non-prescriptive questions are posed in order to maximise the opportunity for the participant to tell their own story and enabling in-depth and new information to be uncovered. However, it is recognised that this is at the cost of the researcher's level of control over the interview as well as increasing the complexity of the analytic process (Smith & Osborn, 2003).

The process of developing the schedule was iterative with my research supervisor and fellow IPA researchers being consulted. The following steps provide a broad outline of how the schedule was generated.

1. Using a 'mind map' three broad issues related to the overall area of caring for an older adult with dementia were identified; these included their work and the factors impacting on it, their identity as a carer, and their beliefs about work.
2. Questions were then generated that related to each area. These questions were discussed and revised in consultation with my supervisor and other IPA researchers.
3. The questions were ordered by a process of 'funnelling' whereby the more general questions about the participants' job and caring were asked before moving on to more personal perspectives on caring. It was hoped that by ordering questions so that more personal experiences were addressed later in the interview, the participant would be more at ease and comfortable with the interview process and researcher and thus greater depth in the participant's responses would be elicited.

4. Prompts were developed for each question. These, slightly more specific, questions aimed to assist the researcher in eliciting a satisfactory response should the initial question be insufficient to do so.

The schedule was learnt by the interviewer. In this way, it could act as a mental prompt rather than the researcher needing to refer to it and disrupting the interview process. This also allowed the researcher to concentrate on what the participant was saying and consider which questions to ask next.

References

Smith, J. & Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp.51-80). London: Sage.

Appendix Q: Consent Form 2

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Exploring care staff experiences (ECSE)

Interview consent form for Care Professionals

We are interested in learning about the experiences of care staff working with older adults with dementia. We would like to hear about your professional experiences of caring for older people with dementia, your views of the work you do as well as your views of yourself as a carer.

Participant Identification Number: _ _ _ _ _ _ _ _ _ _ _ _

Please tick the box

1. I confirm that I have read and understood the information sheet for care professionals (dated XX/XX/XX). I have had the opportunity to consider the information, ask questions and have received satisfactory answers to my questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without penalty or having to give a reason for withdrawing. ☐

3. I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. ☐

4. I understand who will have access to the personal data provided, how the data will be stored and what will happen to the data at the end of the project. ☐

5. I understand that the research will be written up as a student's thesis and understand how personal data used in the thesis will be published and stored. ☐

6. I understand how to raise a concern and make a complaint. ☐

7. I understand that the interview will be recorded and that anonymous quotes from the interview may be used in reports and publications. ☐

8. I agree to take part in this study. ☐

Name	Date	Signature
Researcher	Date	Signature

Appendix R: Reflexive Journal

Reflexive Journal

This reflexive journal aims to describe the integral role of reflexivity throughout the research. As well as situating the researcher, the content below draws upon a reflective diary kept regularly from the beginning of the research ideas to the end of the write-up stage, a bracketing interview and individual post-interview reflections.

Situating the Researcher

Throughout I[15] have aimed to consider my position in relation to the research. I am a 29 year old, White-British female. I have had an interest in psychology since my final years of school and completed my undergraduate degree in this area. Among other roles, I worked as a support worker for people with learning disabilities during my undergraduate degree. Since graduating, I have only worked in the field of psychology. All of my clinical work prior to training was in neuropsychology and neuro-rehabilitation settings. I also undertook an MSc and completed research focusing on the effects of maltreatment on adolescent stress responses using fMRI. As well as a continuing interest in neuropsychology, I have a longstanding interest in working with older people and people with dementia.

In light of the research, it feels pertinent to consider the older people in my life. My grandparents all died during my childhood. Two died when I was 3, one when I was 8 and one when I was 15 years old. Both paternal grandparents had dementia and entered care homes when unable to manage at home. My paternal grandmother, who died when I was 3, was diagnosed with Alzheimer's in her early 60s. I never visited my grandparents in the care home setting but heard stories of their increasing care needs. As

[15] As is the convention in reflective journals, I will refer to myself in the first person throughout.

such, I was aware of the presence of dementia on my father's side of the family from a young age. My father did not have cognitive impairment. He died 5 years ago from undiagnosed cancer. He was in his late 60s. My mother is in her early 70s.

Developing Ideas and the Proposal Process

Excerpt from reflective diary January 2014- Reflecting on reasons for choosing the research. Dementia is a term that I have heard from a young age. One of my earliest memories is of my grandmother who had dementia and being told by parents to be quiet around her. I remember feeling a bit scared but also wanting to ask 'why?' Both my parental grandparents had dementia and entered care homes. The stories about their experiences in care homes are incomplete and I wonder whether this has drawn me to research this area. I also wonder about how my own experiences of caring for others have influenced me. I found support work a hugely challenging role and so perhaps identify with the struggles of direct care workers.

Excerpt from reflective diary January 2014. Research presentation to peers and service users. It is a new area and so large. I had a feeling that I could never know it and was clutching at straws to put things together. After the presentation I had concerns: Am I going to miss something by just focusing on care staff with high levels of self-efficacy? Would it be more in line with 'qualitative philosophy' to be focusing on experiences regardless? But then peers are looking at homogenous groups– it is just the group will be defined by their level of self-efficacy.

Excerpt from reflective diary May 2014. I have been reflecting on developing the semi-structured interview, the questions I want to ask and the questions I have side-lined. This led me to think about the people I have chosen to study. It is interesting that I have chosen to hear the experiences of care assistants at the bottom of the hierarchy

who are doing well. Is this because they are under-represented? Or a drive to want for this group to be seen in a better light? With greater recognition of their strengths?

Excerpt from reflective diary May 2014. I have sent off my proposal to the Research Sub-Committee (RSC). I feel relieved to have taken this step but also anxious – what if there is a flaw in the method or design.

Excerpt from reflective diary July 2014: I got the final OK from the RSC. It is such a relief. I am also feeling more confident because I had 'argued' against one of the revisions and felt that I had been able to do so because of my knowledge of the literature. It feels as though things are coming together, which is exciting. I want to get on with data collection!

Excerpt from reflective diary September 2014. I have had the final go-ahead from CUREC now. This feels like good progress and that now things can move forward. However, it seems like a daunting task.

Ongoing Related Experiences

Excerpt from reflective diary March 2014. We had teaching this week from a psycho-dynamically orientated clinician working with older people. They spoke to a developmental perspective and considered attachment and the regression of older people towards a more dependent state in which they require increased support. The lecturer drew parallels between the way older adults and infants communicate need. I noted my sense of protectiveness towards people who are in need and trying to communicate but may, as a consequence, have negative narratives built up around them.

Excerpt from reflective diary May 2014. I saw a client in a residential home with my supervisor as part of placement. The client was quite agitated and staff said that

she rang her bell often. However, the care assistant we met with was extremely positive and described enjoying working with the client. She reflected not being aggravated by the bell-ringing but believing that the client was just trying to communicate. I was struck by her dedication and patience and wonder whether this is a view that I might naturally take towards staff in difficult situations.

I was aware of the power imbalance and the member of staff looking towards my supervisor for approval. It led me to reflect on my role and how I may experience this imbalance with participants. I wonder how this might affect the information, experiences, thoughts and feelings that staff choose to share and how I might be able to manage that.

Excerpt from reflective diary June 2014. I have been to the Faculty of the Psychology of Older People conference. There was a focus on dementia. It was nice to be immersed in relevant research. Research was presented that highlighted the need to think about wellbeing in care staff which was hugely validating and increased my enthusiasm.

Excerpt from reflective diary September 2014. I was involved in training for health professionals supporting people in care homes. It was a useful context for thinking more broadly about care homes and care home staff. I was struck by the issues discussed by health professionals in relation to care staff. For instance that care staff may not initiate or follow-through with recommendations. I noticed it brought out a more defensive reaction in me when I was role playing a member of care staff and the team members interviewing me did not seem to acknowledge the time pressures that I might be under, the competing demands or my emotions about my work. I wonder if this reflects my want for the struggles of staff to be recognised.

Starting Recruitment

Excerpt from reflective diary early October 2014. I have had two positive responses from care homes interested in taking part in the research. The managers' enthusiasm is great but I do not want their staff to feel obliged to take part or coerced so I will have to emphasise their choice in this.

Excerpt from reflective diary mid-October 2014. I dropped off some study packs at a care home today. I noticed I felt a bit awkward waiting for the manager in the care home. It reminds me of an article my supervisor gave me which highlighted the need to be familiar with care homes and the staff to conduct research in this setting. I wonder the extent to which not being very familiar with the homes I am researching in may have a positive impact, in terms of people feeling freer to speak, or rather a negative impact, in terms of being a less-trusted outsider. I was struck by how when I explained to the manager that I was interested in staff's experiences of caring for people with dementia she simply said - 'tiring'. She also suggested that I should be focusing on managers' experiences. She outlined her main concern being that care staff don't take responsibility and that she wanted to know how she could facilitate them to accept responsibility. I felt defensive of care assistants who I view as already in a position of responsibility with little recognition at times[16].

Excerpt from reflective diary November 2014. I am writing up my method and I am wondering on reflection whether I have been a bit too explicit in my interview questions. It didn't feel so when I was writing them but that was nearly 6 months ago and I now have increased knowledge of the area as well as of qualitative methodology

[16] Reading back through my reflective journal, I am struck by the view that care assistants should take on more responsibility. My sentiment that they already hold a great deal of responsibility continues to resonate at the end of this research.

and IPA analysis. Perhaps they are too loaded? Am I really entering their world? Or am I trying to get them to enter mine? I will try to remain aware of the questions asked when interviewing participants and analysing the results.

The Bracketing Interview

The bracketing interview was conducted by a peer and explored my interests in this area, as well as assumptions, biases and expectations, hopes and fears.

For instance, the interview was valuable in highlighting my initial thoughts and biases about the IPA methodology.

Interviewer: Do you have any experience of IPA or is it a new thing? What sort of feelings and thoughts do you have about the results section?

Respondent: I was reading through some the other day, which, um, different quotes you pull out and... it feels so subjective. It is just thinking about, actually, how can I make it rigorous? I think that the idea about being rigorous comes from a possible bias towards quantitative research, being systematic and I've found it quite hard just to sit with the uncertainty. I have realised that I have placed greater value maybe on quantitative research, on hypothesis testing and empirical studies and so there is something that I feel I need to justify to myself. I remember, a few years ago, listening to a trainee present their IPA study and just thinking "well, this is a bit wishy washy". I think, um, it is my justification to the people out there who I assume are thinking... "oh, why she doing that? that's a bit wishy washy".

My choice of methodology as well as the context of the data collection was also explored.

Interviewer: I was wondering specifically why you went for IPA and 1:1 interviews… was there a rationale for that?

Respondent: I thought actually maybe a focus group or something would be good and then do thematic analysis or IPA. There has been, um, research looking at care staff that, kind of their experiences of work using focus groups... so there was a thought that maybe I should build on that, and do that, but then I was worried that they wouldn't actually, people wouldn't open up as much, and I wouldn't get as much information, I wouldn't be able to really get into their experiences which is what I wanted. So it felt that actually an individual interview and then with an IPA analysis to really draw out those themes would be the best thing.

Interviewer: So that for you led you to thinking a 1:1 might provide sort of more depth? What do you think it is about 1:1 interviews that might allow people to be more open?

Respondent: I mean if I think about... well, it is a bit different I guess, with us at work because we are psychologists, we are used to reflecting, but if I think back to the past about working in teams and actually the ability to say how you are finding something, saying that you are finding something hard can be quite a difficult thing to do and thinking about different power dynamics within the team that I wouldn't necessarily be aware of due to being an outsider. I thought, that could be quite a challenge, um, and trying to get an equal voice from each person if I didn't know them... that would be quite hard. So, I guess it was a combination of things.

The interview elucidated personal narratives that may have drawn me to this research.

Interviewer: I guess I was thinking about you, you as a person, and like your history and background and is there anything you think about yourself that's going to affect how you might see the data or analyse the data? Have you thought about that, that sort of sort of thing?

Respondent: I have been thinking about that. I have been keeping my reflective, kind of log thing, and I guess thinking about my grandparents on one side of my family, my dad's side of the family, they both had dementia and they were both in care homes. Yeah, so I think there is like a personal interest in it, in terms of wanting to understand. I remember thinking the care staff there might not be doing the best job, or just, having the kind of feeling that it wasn't a nice place to be. I think with the media as well you, kind of, get that impression.

Interviewer: What do you think allowed you to empathise with those people then, rather than feel angry towards them?

Respondent: It was probably, because my both grandparents died before I was working. It was really when I was in that position, working as a support worker, and being in a position of doing a not particularly, um, well paid job but being faced with quite a lot of responsibility and, you know, quite a few challenges I thought actually that is a really, really, hard job to do and then I have had other older people in my life, like family friends, who have been in care homes. And I have seen them treated really well, um, and thinking about, what is it that enables them to do that and how and actually thinking back to it... now I reflect back, knowing more, my grandfather may have been really difficult in the care home. So they must have been in a really difficult position. Not very well supported potentially and actually they probably did do a very good job.

Having transcribed the bracketing interview, I took time to reflect on this process within my reflective diary

Excerpt from reflective diary November 2014. I noticed that I used the word rigorous a number of times. I do wonder about how I view IPA and qualitative research. I think my past experiences of research and their quantitative nature may be lead me to falsely think there should be 'neat' answers. Also, I am aware of past voices, such as old supervisors, and people around me currently that view qualitative research negatively. However, I do think it has huge value in gaining knowledge of a person's experience and the meaning they ascribe to this- really getting the depth of that which wouldn't be possible with quantitative research. I want to place more faith and belief in the methodology.

Prior to data collection I also created a mind map of what I imagined care staff experiences might involve. This provided another layer of 'bracketing':

Data Collection

During the data collection phase, individual reflections post-interviews were completed in order to capture the feelings and thoughts about individual participants.

These reflections considered the flow of the interview as well as responses to the questions asked. Such reflections seemed particularly pertinent at the beginning stages of data collection when reflecting on the efficacy of the interview schedule.

> *She gave some quite short answers. I wasn't sure if this was due to the nature of the questions or rather because she was less willing to talk about herself. It*

maybe seemed safer to stick with talking about work. I am aware from my bracketing interview that I had thought that staff might focus on talking about work. I think I need to be aware of the fact that care assistants may not be in the habit of reflecting to the level that we do as psychologists. If I think back to being a support worker, I was not supported or encouraged to reflect and might have struggled to engage in reflecting about my work. (Reflecting on the interview with Jenny)

I noticed the contrast to my first participant in terms of her openness and her understanding of me wanting to find out about her. I think this probably also reflects the fact that I was much less anxious during this interview and therefore probably set her at ease. (Reflecting on the interview with Gayani)

A source of reflection was also rapport I had with clients as well as my emotional reactions to them and their narratives.

I liked her from the start. She was warm and friendly. There were moments such as when she was talking about residents' faces lighting up, the bond she has with them and treating them like family that I was particularly touched by. (Reflecting on the interview with Maria)

She had quite strong opinions and views on how things should be done and I felt at times that she was trying to draw me to respond to these. I found some of the stories told quite difficult to listen to. This wasn't necessarily due to the content; in contrast to participants who spoke candidly about loss, it was her use of quite evocative language that seemed to spark a reaction in me. She used the word 'abuse' a number of times and this led to me exploring risk with her after the interview.[17] *It felt odd to make this shift. It is not something that I have had to do with other participants and it seemed to enhance the power differential. (Reflecting on the interview with Carol)*

I felt a particular identification with one care assistant and this was a source of reflection following the interview.

I felt quite protective of her being younger. When she was talking about difficult experiences of aggression and loss I felt a sense of admiration for her. She was so young in my mind when she have started such a challenging job. I identified with her experience of increased separation from her friends due to her differing

[17] The protocol for managing risk laid out in my ethics application was followed. This involved encouraging Carol to raise her concerns with her manager, which she had already done. As a precaution I also consulted with my supervisor. I was anxious about ensuring that I had completed the appropriate steps. This process brought power imbalances to the fore and created some discomfort for me. However, the importance being aware of ethics throughout the research process was highlighted.

outlook on life as a result of her experiences. Maybe it relates to the impact that differences in perspectives, as a result of my work, has had on my relationships with some old friends. (Reflecting on the interview with Emma)

The emotions and thoughts evoked by care assistant narratives about my own position were a further area of reflection.

I was also struck by her mentioning her religious beliefs and the role they play. It was not something, when starting out that I had thought about. I led me to reflect on my own religion. Whilst I would not describe myself as religious, my mother is. She attends church every Sunday and is involved in Christian charities, helping others, informally caring for older people in her community. Perhaps I have been more exposed by this motivating force than I first thought. (Reflecting on the interview with Gayani)

Within post-interview reflections, I considered the questions I did or did not ask, whether there were any that I had avoided and which accounts and narratives stood out.

I noticed that I didn't ask about the recent loss of her key client despite her referring to this several times and it being in my mind for much of the interview. (Reflecting on the interview with Jane)

She spoke about her culture and large family but I noticed I didn't ask more about this. I also noticed that I was drawn to ask her about death of residents. This is something that has come up with other clients and something I find interesting so I wonder about the extent to which it matters to her. (Reflecting on the interview with Maria)

I also reflected on the relation between participants and the degree to which my questions may have been shaped by previous interviews as well as considering the changing perceptions of care more broadly.

I wonder whether there are differing cultural values that lead to the sense of commitment and responsibility and understanding she described. I noticed thinking about the possible overlap between Diwa and Gayani. Given the similarities between these two, I found myself tempted to ask her about religion as a means of support. Although I didn't, it highlights a possible generalisation I might make, and should be aware of, particularly when moving between the analysis of one participant to another. (Reflecting on the interview with Diwa)

The post-interview reflection also considered the degree to which there may have been a power imbalance within the interview. Across interviews I held the more powerful position of the researcher but further imbalances may have arisen due to differences with our positioning in relation to Burnham's 'Social GRACES'.

The whole group and the care assistants' positioning in a wider social context was also a cause for reflection.

> *I had the sense that this was more than a job for her, it is more than money. I notice myself becoming frustrated – why are people doing such difficult jobs not more supported or better paid? The interviews highlighted that this is skilled work that is not necessarily rewarded or acknowledged. (Reflecting on the interview with Pauline)*

I also reflected on emerging themes within the data and the way in which I was starting to make sense of care assistants' experiences.

> *I am starting to form some themes in my head about vulnerability as well as making sense of behaviour. Care assistants' interpretations of residents' behaviour seem important; a strong narrative is that "it is not their fault". (Reflecting on the interview with Jane)*

Ideas emerging about broader implications of what the participants were saying were also noted.

> *I was really struck by her reflection that it had been useful to share, to get it off her chest. This prompted me to firstly reflect on my style and whether I had moved out of a researcher role. However, I went on to consider whether it reflected a lack of reflection and discussion in care homes. I wonder how little staff sit and talk particularly about the death of residents or aggression which seem to be two particularly challenging areas. I found myself reflecting on the use of reflective groups and how these might be incorporated into care homes. (Reflecting on the interview with Maria)*

Interestingly, the majority of care staff asked to be interviewed at their place of work. Therefore the care home and potential generalisations between participants from the same care home were also considered.

> *One care home, in which two participants worked, seemed really forward thinking and the layout and design of the place reflected this. I wonder about the impact this had on the values and approach of staff.*

Following the transcriptions, all of which I completed myself in order to engage fully with the data, I also reflected on which answers I did or did not hear during the interview as well as considering the flow of the interview and the emotions it brought up for me.

> *At the time, I didn't find myself having particularly strong emotional reactions to what she was saying. However, when transcribing the interview I felt sad listening to some of her stories. (Reflecting on the interview with Jane)*
>
> *There have been parts of her interview, when listening back and transcribing, that were really emotive for me. When she spoke about residents who don't have any family and the emotions this brings up in her, I also had a sense of sadness. (Reflecting on the interview with Pauline)*

Data Analysis Stage

I had reflected on concerns regarding data analysis from early in the research process.

Excerpt from reflective diary May 2014. I think there is a risk that I might fall into over-analysing – ruminating, deconstructing and not getting anywhere. This is alongside a concern that my results might be too abstract and not meaningful.

When the time came for analysis, I seemed to be held back by my own anxiety and want to get it right.

Excerpt from reflective diary March 2015. I have started analysis. I am getting into the data and feeling so much more engaged with the research. The difficulty I have found, is my desire to 'get it right'. Reading through the transcripts, I am struck by the care assistants' honesty and openness as well as the challenges they face. Some have spoken about not having the opportunity to talk about their experiences. I feel even

more driven to make sure that I do a 'good job' of giving them a voice that represents their experiences. In doing so, I become stuck at points and find it hard to see the wood for the trees.

Excerpt from reflective diary April 2015. I initially adopted the IPA method in the Smith, Flowers & Larkin book – this was containing due to the level of detail in the book but I found myself being quite descriptive and becoming concerned about being pithy and concise with the emergent themes which led to me seizing up. Taking a step back, having teaching from Michael Larkin, reading an article by Larkin, Watts & Clifton (2006) and thinking more broadly has been helpful. I have a much better grasp of the philosophical stance of IPA and the core principles of the approach. It was freeing to have it highlighted that there are a number of different ways of approaching analysis. I just need to focus on meeting the core principles and find a way that fits for me. So, two transcripts in, I started the analysis again and it feels that adopting the approach Larkin described, I will be able to better represent what matters for the participants as well as what this means.

Excerpt from reflective diary May 2015. For the past month I have been meeting with a peer on a weekly basis to discuss the methodology, emerging ideas and themes. Interestingly, we have adopted a very similar approach having found the one detailed in the book limiting. I was struck by how much more sense I was able to make, and how much more interpretative I could be, with someone there to bounce ideas off. Given my tendency to describe, and lack of confidence in being more interpretative, discussions were particularly valuable in increasing this aspect of the analysis.

Excerpt from reflective diary May 2015. Undertaking the analysis, I have been aware of the breadth the interviews. Focusing on one aspect of dementia care may

have increased the depth and richness. However, the lack of literature in this area was a motivator for the research and perhaps focusing on one aspect of carers' experiences would be something for future research.

During coding I have been struck by accounts of aggression, distress and death and at times have become emotional. I have an admiration for the staff as well as a feeling of injustice arising from the lack of recognition this group has and the lack of understanding regarding the dilemmas they face. I wonder whether this will come out in the overall structure.

As I have continued with coding, I have a growing anxiety about how I am going to reduce the data into something meaningful. With so much data, inevitably some with get lost and my thorough approach to the analysis makes this reality uncomfortable.

Excerpt from reflective diary May 2015. I met with my supervisor to look over emerging themes. She had read through all the transcripts and done initial coding for them all. She reflected being surprised by some of the narratives. Her interest in the findings increased my sense that the results are novel and worthwhile. During the process I have been concerned about how I can approach analysis with as open a mind as possible. Comparing my own and my supervisors' expert perspectives highlighted my relative naivety about the literature yet biases and assumptions are still present.

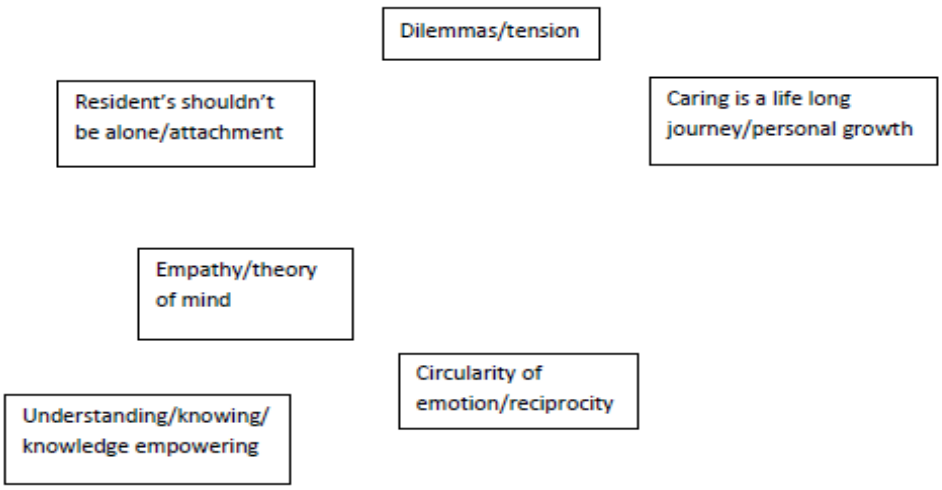
My supervisor and I noticed that one participant provided a contrasting account to others. Carol's interview had a different quality in terms of her frustration with the system. This presents a challenge for analysis. Her experiences need to be heard. However, the strong views of one may impact on the themes that emerge. Interestingly though, beneath her anger and frustration is concern which echoes other narratives.

However, I need to be aware that teasing out these aspects may represent a greater degree of interpretation than that I have afforded other transcripts.

It was also interesting to think about what the expert role I have in terms of having conducted the interviews and knowing the data best. This was highlighted when my supervisor questioned some participants' descriptions of residents as 'these people' and possible 'us' and 'them' divides. We discussed the impact of English as a second language and the evidence of her view of the residents for whom she cared. It was my sense that this was not an intentional use of the words. Following the discussion, I felt an increased confidence – being there and knowing the people I interviewed provides a huge advantage and I should trust in my sense of how it was.

Excerpt from reflective diary May 2015. I have spent the last two days doing the across case clustering for the analysis. Whilst I thought it was going to be a difficult task, clusters of ideas began to emerge. I had not been aware of the extent of concordance between participants on some of these ideas until I got to this stage.

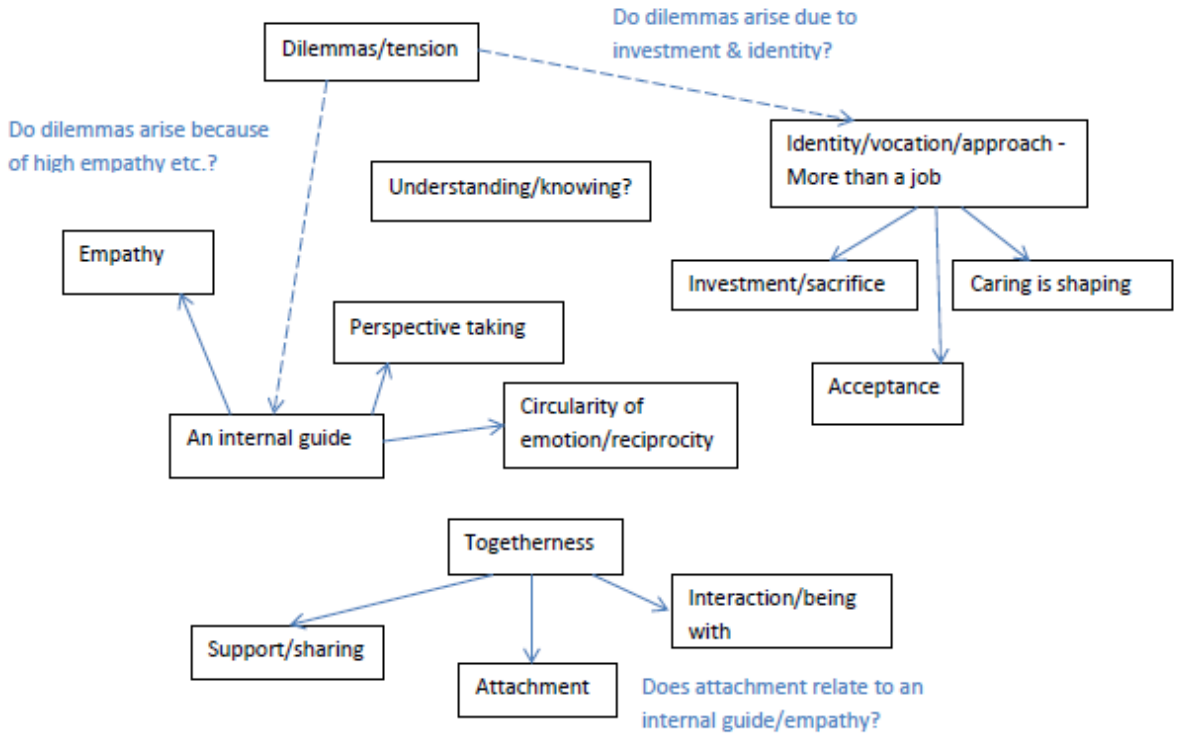
Initial clusters taken from audit trail:



With time, related ideas could be clustered under broader themes. For instance, I became aware of repeating ideas about connection, empathy and investment. Both myself and my supervisor also noticed particular patterns relating to ethical dilemmas and circularity in emotion.

The togetherness/connection cluster that emerged seemed quite clear. The circularity, empathy and perspective-taking seemed also to form a related group. I found that I wanted to group the dilemmas with other ideas. For instance, do dilemmas arise because of people's identity or investment in care?

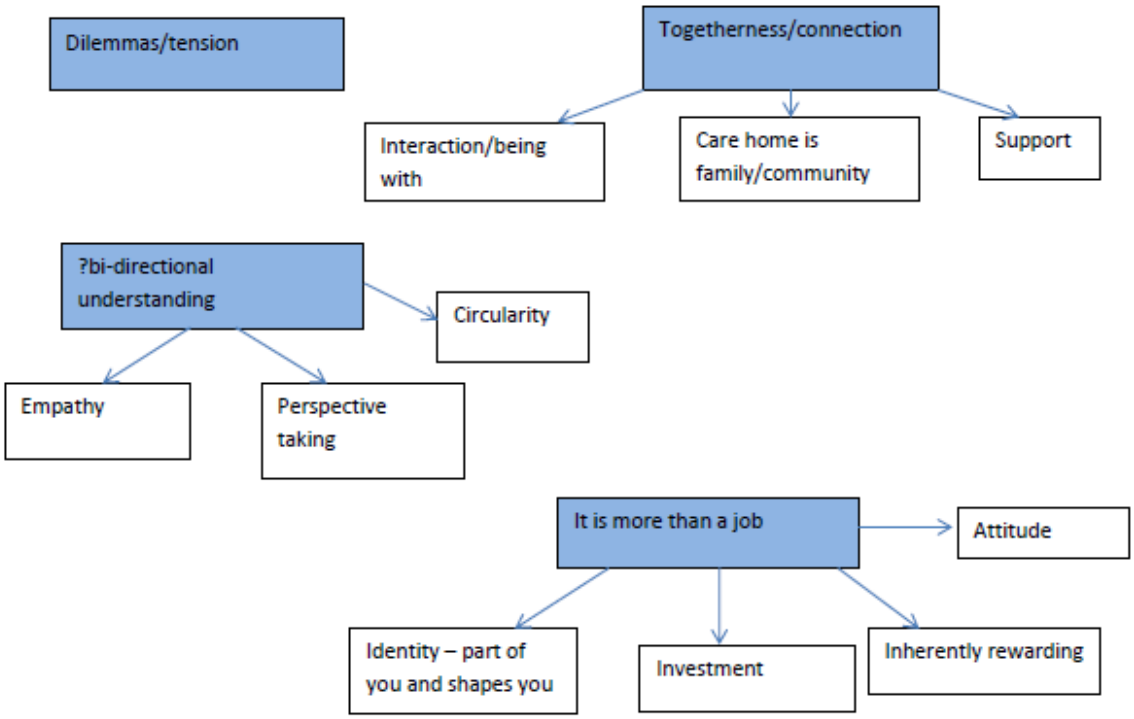
Emerging themes taken from audit trail:



It is interesting because the number of dilemmas mentioned by the participants was striking. In looking back at my bracketing interview, I noticed that I had said that I

was unsure whether I would hear about the struggles that people are having. This was not the case, I certainly heard from participants about their struggles and dilemmas.

Preliminary structure taken from audit trail:



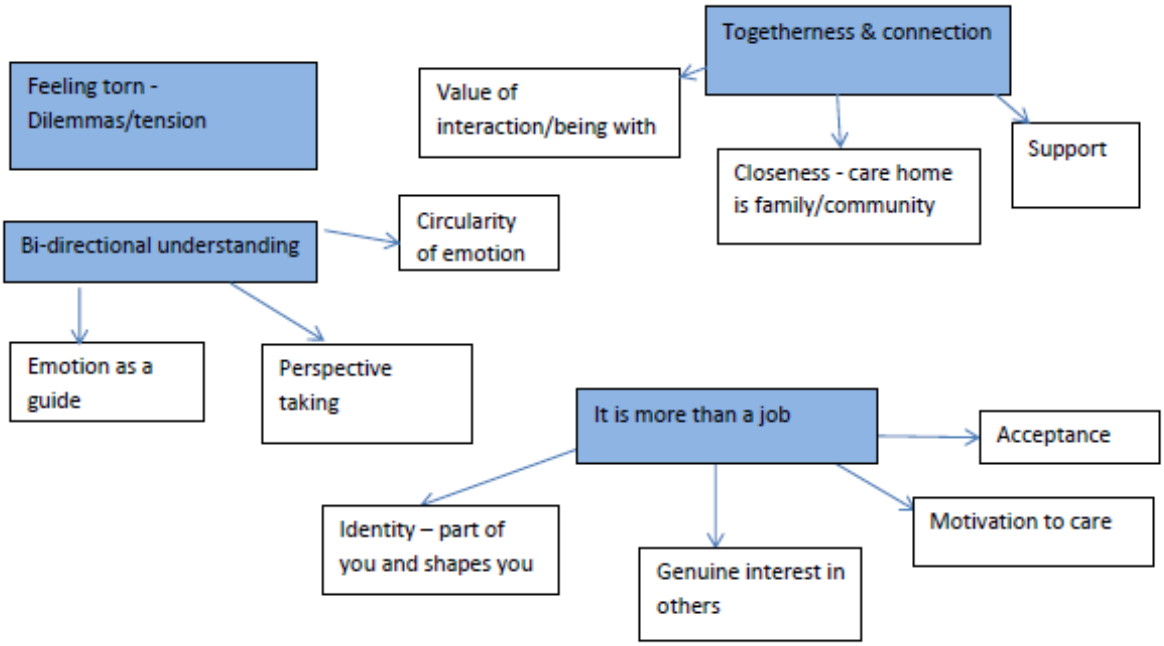
Michael Larkin's words about how many themes to have and not to have too many came to mind as I stared at the smallest amount I seemed to be able to reduce it to – 12. However, each theme does seem to represent something particular rather than being repetitive. I wonder whether it is a reflection on the breadth of my research study and the questions asked.

I am excited with the results that I have generated. I had feared and written earlier in the log about regurgitating themes that simply reflected the questions I had asked. I also feared that my coding was too concrete and not interpretative enough and

that this would limit the subordinate and superordinate themes. So it was really nice to see novel, unexpected and interesting themes emerge.

In speaking with my supervisor and a peer I refined the themes. Notably, was the shift in the superordinate theme of it being 'more than a job'. It felt important to capture a genuine interest in others in its own right in light of the dominance this had in all narratives.

Final structure taken from audit trail:



I am keen to get writing up and putting quotes to the themes to bring them to life.

Writing Up and Coming to a Close

Excerpt from reflective diary June 2015. I am writing my discussion and thinking about my results in a broader context. I have been reflecting on some of the narratives that didn't make it into themes and whether something was lost because of this. Should I have included more? Have I left out important parts? I am particularly

struck by the two narratives about care staff not being acknowledged. As Jane highlighted:

> *You got a carer that you, that slaps people, that's going to get publicity, that's going to get the papers selling as opposed to one that is getting slapped and doesn't raise, raise their hand, or, or anything, just tries to keep everything calm. Which would, what would, what are you going to read, what one are you going to. Two papers, one of a care home where the care staff are really good and one of a care home where the care staff couldn't care less and the one that's going to sell more papers is the one that couldn't care less. (Jane)*

This quote feels so evocative and reflects one of the reasons I wanted to hear the voices of this group as well as the sense of injustice I noted earlier in the reflective log. I worry that I may have colluded in this lack of acknowledgement by not including this as a theme. Whilst it was only in two narratives it feels like a powerful contextual point.

I have also been aware of the theme of communication, which runs through the narratives but was not regarded as a theme in its own right. I hope that it is captured in the write-up.

Writing up, I have been aware of the language I used to label themes. Some quotes perfectly captured the theme but others seemed more abstract. It was with this reflection that I changed the superordinate theme 'bi-directional understanding' to 'attunement'. This seemed more grounded in the care assistants' experiences.

Excerpt from reflective diary end of June 2015. I have got the first full draft done and had feedback on this. It is starting to feel like it is all coming together. People have reminded me to 'have my voice in' the write up but this has been hard. I thought about using the first person to make my voice more active. I read an IPA paper and it read well in the first person but I am apprehensive this seemed like a shift and out of line with past dissertations.

Excerpt from reflective diary July 2015. I have a draft of everything but am now having to cut down on the words. It is so hard to cut out the care assistants' quotes. I have realised how attached I have become to some of their stories and I am very conscious of wanting to a 'good job' of representing their voices which makes this stage really difficult.

Appendix S: Rationale for Choosing Interpretive Phenomenological Analysis (IPA) and Background of this Methodology

Background to IPA

IPA adopts a phenomenological stance. As such, it aims to gain an understanding of how events or objects are understood by an individual rather than seeking an objective truth about an object or event (Smith, Jarman, & Osborn, 1999). However, it is recognised that in order to make sense of an individual's subjective experience, the researcher is required make interpretations about their personal world (Smith et al., 1999). Therefore, a core feature of IPA is that it is also interpretative.

Rationale for Methodology Adopted

A qualitative methodology was adopted with the aim of increasing understanding, and make sense, of care staff's experiences of providing care, their motivations and what it is that enables them to feel competent in their caring role. In doing so the research hoped to 'give voice' to the claims and concerns of dementia care staff. With an overarching aim of reaching a fuller understanding of how particular people make sense of their experiences in a particular context (Larkin & Thompson, 2012), IPA was felt to be the most appropriate methodology for the current research.

The suitability of other qualitative methods was considered; for instance, existential-informed hermeneutic phenomenology. However, this methodology is particularly suited to questions concerning major life events, transitions and ways in which individuals' process fundamental existential concerns (Willig & Billin, 2012), which was less relevant to the broad experiences of dementia care staff.

Grounded theory, which focuses on individuals' interpretations of their experiences with the aim of developing an inductively driven theory of studying basic social or psychological processes (Glaser & Strauss, 1967), was also considered. Whilst grounded theory could be considered a suitable methodology, the aim was not to develop a theory about self-efficacy particularly given that well-established theories relating to self-efficacy already exist.

Discourse analysis could also have been adopted to research this group. This social constructionist approach examines how reality and experience are constructed through social and interpersonal processes (Georgaca & Avdi, 2012; Starks & Brown Trinidad, 2007). Whilst this approach may illuminate how different discourses shape personal and group identities, as well as how staff negotiate social interaction and relationships, it would not provide a broader understanding of the features and meaning of providing care to older people with dementia.

Narrative analysis centres around the study of individuals' stories or accounts of experiences. Whilst similarities could be drawn between narrative analysis and IPA, narrative analysis focuses on the structure, use of language and connections within narratives (Murray & Sargeant, 2007). This approach may enable the researcher to locate the experience within a broader life course perspective. However, narrative analysis may be more limited in elucidating the inherent perspectives that staff have regarding dementia care.

Finally, the use of focus groups, and subsequently content analysis, was also considered. However, it was felt that this format may hinder communication related to individual experiences.

References:

Larkin, M. & Thompson, A. (2012). Interpretative Phenomenological Analysis. In A Thompson & D. Harper (Eds.) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 99-116). Oxford: John Wiley

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Jersey: Transaction Publishers

Georgaca, E. & Avdi, E. (2012). Discourse analysis. In A Thompson & D. Harper (Eds.) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 147-161). Oxford: John Wiley

Murray, M., & Sargeant, S. (2012). Narrative psychology. In A Thompson & D. Harper (Eds.) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 163-175). Oxford: John Wiley

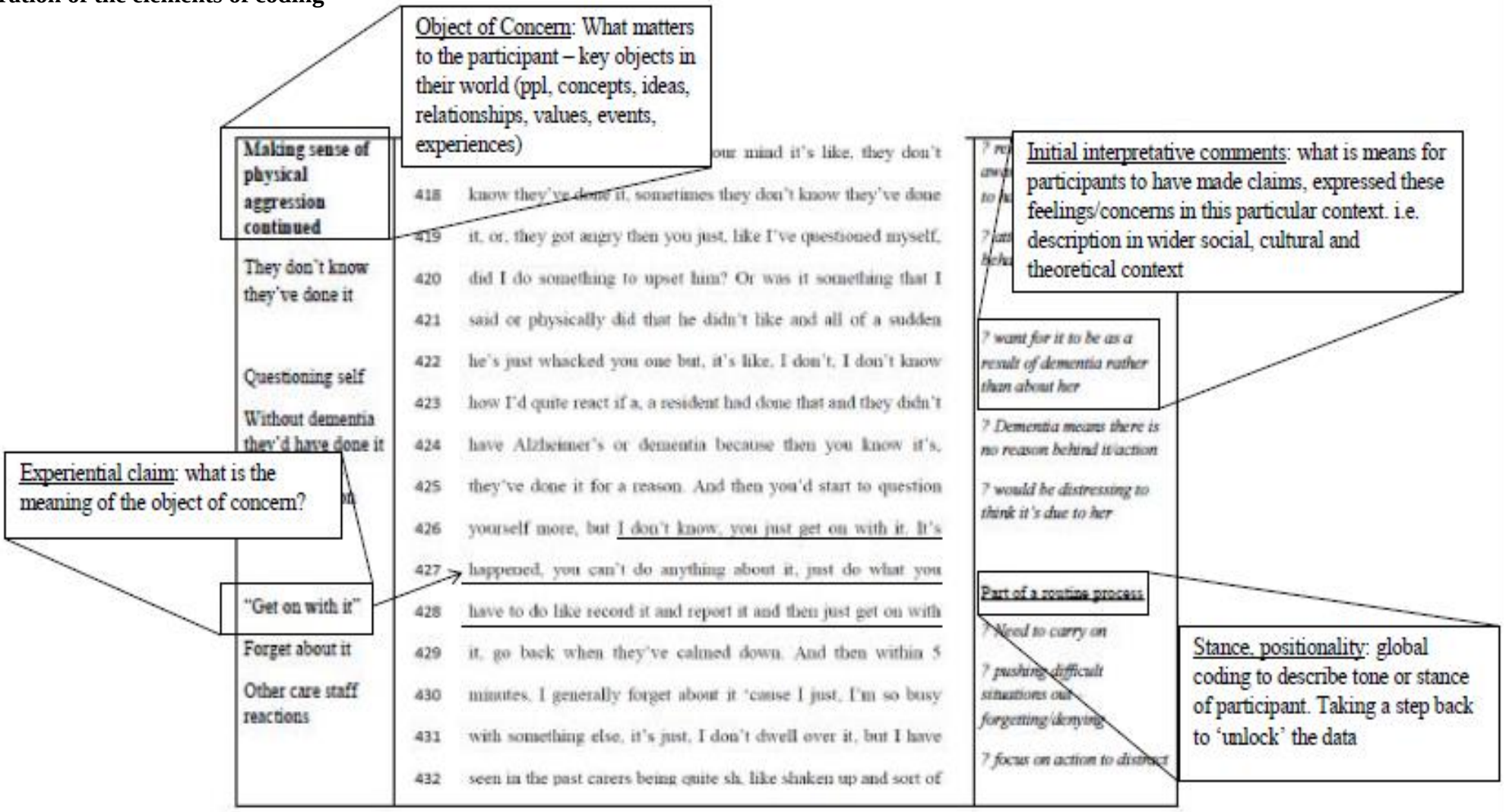
Smith, J., Jarman, M. & Osborn, M. (1999). Doing interpretive phenomenological analysis. In M. Murray & K. Chamberlain (Eds.) *Qualitative health psychology*. (pp. 53-80). London: Sage.

Starks, H., & Bown Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, doscourse analysis and grounded theory. Qualitative Health Research, 17, 1372-1380. doi: 10.1177/1049732307307031

Willig, C., & Billin, A. (2011). Existentialist-Informed Hermeneutic Phenomenology. In A Thompson & D. Harper (Eds.). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioner.* (pp. 117-130). Oxford: John Wiley

Appendix T: Example of Annotated Transcript

Illustration of the elements of coding



Making sense of physical aggression continued They don't know they've done it Questioning self Without dementia they'd have done it for a reason – would question more "Get on with it" Forget about it Other care staff reactions	417 418 419 420 421 422 423 424 425 426 427 428 429 430 431 432	whatever. But in the back of your mind it's like, they don't know they've done it, sometimes they don't know they've done it, or, they got angry then you just, like I've questioned myself, did I do something to upset him? Or was it something that I said or physically did that he didn't like and all of a sudden he's just whacked you one but, it's like, I don't, I don't know how I'd quite react if a, a resident had done that and they didn't have Alzheimer's or dementia because then you know it's, they've done it for a reason. And then you'd start to question yourself more, but I don't know, you just get on with it. It's happened, you can't do anything about it, just do what you have to do like record it and report it and then just get on with it, go back when they've calmed down. And then within 5 minutes, I generally forget about it 'cause I just, I'm so busy with something else, it's just, I don't dwell over it, but I have seen in the past carers being quite sh, like shaken up and sort of	*? residents lack of awareness makes it easier to handle* *? attempt to understand behaviour* *? want for it to be as a result of dementia rather than about her* *? Dementia means there is no reason behind it/action* *? would be distressing to think it's due to her* <u>Part of a routine process</u> *? Need to carry on* *? pushing difficult situations out – forgetting/denying* *? focus on action to distract*

Appendix U: Excerpt of Participant Map

Objects of concern – things that matter in their lif e world/objects in their life world e.g. people place, concepts, ideas	Experiential claim – what the meanings for the person (often looking for linguistics to identify that).
Main interpretive points - Possible ideas of what this might relate to	Page/line n – [paraphrase] or quote
Making sense of physical aggression Dealing with aggression becomes part of routine Locating behaviour in dementia removes the intent of aggression Concern and questioning regarding own role in resident's behaviour	18/398 - it's happened to me before, the resident hasn't had a clue what they've done 18/399 - this one time I was scratched on the arm, quite badly. He drew blood and, he didn't have a clue what had, what had just happened 18/403 - left him in the bed, safe and then… went off for a minute and… just checked my arm, cleaned it up, just told the nurse and got back to my job 18/406 - them not reacting for me was probably easier for, for my, sort of like, emotion... he doesn't know he's done it, that's fine 18/415 - It helps that you know that they have Alzheimer's or dementia. Not that that's a good excuse for them doing it or whatever. But in the back of your mind it's like, they don't know they've done it 19/419 - I've questioned myself, [was it something I said/did] that he didn't like and all of a sudden he's just whacked you one 19/422 - I don't know how I'd quite react if a, a resident had done that and they didn't have Alzheimer's or dementia because then you know it's, they've done it for a reason. And then you start to question yourself more. 20/444 - you can't question the resident over why they did it, they don't know 20/448 - you could, sort of like, talk to colleagues about what you're feeling like 20/449 - See if anyone else has had the same experience and maybe it might have been something you've both done the same that he didn't like and he's hit both of you for it and you might learn something from each other 20/453 - but most of the time you just rub, just go, let it go over your head… I might think about it for 5 minutes and then I've forgotten so wait until it happens again
Managing challenging behaviour Communication and responding to needs are ways of reducing challenging behaviour Knowing and understanding individual residents gives confidence to manage challenging behaviour	20/461 - the violence situations, they're, they are tricky 'cause you never know when, you never know when to expect someone to lash out but there are ways around trying to calm somebody down before they get so irate 21/465 - talking to them slowly, and explain every single thing that you, you're going to do or need to do… get them to help as much as they can 21/471 - You see somebody that's not in a very good mood that's sat in a lounge with 20 people and they're getting, they're boiling up, you know just take them away. 21/474 - Rather than upsetting everyone else, just take that one person away and calm them down, before it gets… to the point where they feel like they need to lash out 21/477 - all the residents are different it's just, they've got their own little way and once you know that, you'll, you'll be absolutely fine but it's like, I dr, I don't know what I would feel like if I was new in that situation, not really knowing that person or anything like that, that I imagine would be quite tough

Appendix V: Account of Credibility Checks

A number of steps were taken in order to maximise the credibility of the research. These are detailed below.

Service User Feedback on Developing Ideas

The developing research idea was presented to colleagues as well as to service users. On the basis of the feedback and questions asked, research ideas were re-considered and refined.

Feedback on Interview Schedule

General discussions regarding the interview schedule took place with a peer group of IPA colleagues. Further discussions took place with the researcher's supervisor. Revisions to the interview schedule were made on the basis of these discussions and the researcher's reflections on the discussions.

Discussions with IPA Colleagues

The researcher met with an IPA peer group on a number of occasions. Time was allocated to meet with a peer and carry out a pre-study, 'bracketing', interview. This explored reasons for undertaking the study as well as expectations and assumptions.

During the data analysis stage, the researcher met with a peer on a weekly basis to review transcripts, initial noting and coding. Subsequently, meetings considered emerging themes for each participant. This included themes being reviewed by a peer and discussing differing views and interpretations of participants' experiential claims. Towards the end of data analysis, discussions were then had regarding the ways in which subordinate themes may relate and the emerging structure of themes.

Meetings with Research Supervisor

The researcher met regularly with their supervisor to promote reflection, verify ideas and consider emerging themes. Initially the supervisor reviewed coding of part of one transcript to verify and discuss differences. The supervisor also read and made initial notes for all transcripts. Emerging themes generated by the researcher for each transcript and the development of the final theme structure were discussed. This constituted a crucial part of the iterative process in developing themes.

Discussion with IPA Expert

During the data collection and data analysis phase the researcher met twice with an IPA expert to discuss conducting interviews, the interview schedule, the process of coding and development of themes.

Audit Trail

An audit trail was created for the whole analytical process. Thus, a document detailed the process that encompassed the initial notes made on individual transcripts through to the final set of themes.

Appendix W: Letters of Ethical Approval and Sponsorship

Oxford Health NHS
NHS Foundation Trust

The Oxford Institute of Clinical Psychology Training

UNIVERSITY OF OXFORD

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
Tel: +44(0)1865 226431
Website: www.oxicpt.co.uk

3rd July, 2014

Alice Coates
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre

Dear Alice,

Thank you very much for your letter via email, and also for clarifying my query so quickly. You now have full approval for your dissertation project, and we wish you all the best with your study.

Yours sincerely,

Dr Myra Cooper
Senior Research Tutor

c.c. Jane Fossey

Senior Research Tutor: Dr Myra Cooper, M.A. (Hons)., M.Phil., D.Phil., C.Psychol. Tel: (01865) 226375
myra.cooper@hmc.ox.ac.uk

acoatesdissapp

MEDICAL SCIENCES INTER DIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford

University Offices, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577 Fax: +44(0)1865 280467
ethics@medsci.ox.ac.uk http://www.medsci.ox.ac.uk

CONFIDENTIAL

Ref: MSD-IDREC-C1-2014-134

Miss Alice Coates
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
University of Oxford
Warneford Hospital
Oxford

27th August 2014

Dear Alice

CUREC checklist

I am writing to acknowledge receipt of your CUREC-1 form for your project: **Caring for older adults with dementia: the experiences and perceptions of care staff with high levels of self-efficacy**

On the basis of the information you have provided this has now been approved by the Medical Sciences IDREC **subject to:**

a) **it is your responsibility to comply with the requirements for administering any tests or questionnaires and if in doubt to contact the publisher of those tests or questionnaires.**

The reference number for this project is **MSD-IDREC-C1-2014-134** and is valid for a period of **13 months** from the CUREC 1 approval date, **27th August 2014**. Please may I remind you that your project may be reviewed at some stage during an annual audit of projects.

Amendments

Should you at some stage alter some of the techniques or procedures then you should first undertake a checklist (CUREC-1) to see whether these changes alter the ethics of the research. If these remain the same then the committee will require notification of the changes to lodge with the project. If they do not remain the same then you may need to complete a CUREC-2 form and undergo further scrutiny by the committee.

Please do not hesitate to contact me if you have any queries about this.

Yours sincerely

Gill Halstead
Research Ethics Co-ordinator, Medical Sciences

MS IDREC
Research Services, University of Oxford

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ethics@medsci.ox.ac.uk http://www.admin.ox.ac.uk/curec/

CONFIDENTIAL

Miss Alice Coates
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
University of Oxford
Warneford Hospital
Oxford

13th February 2015

Dear Alice

MS-IDREC-C1-2014-134: Caring for older adults with dementia: the experiences and perceptions of care staff with high levels of self efficacy

Thank you for submitting a request for amendments to the above project.

I am pleased to confirm that your requests to:

- revise the Participant Information Sheet, to stipulate where the interviews can take place
- send a letter to participants to clarify who will be contacted after completion of the questionnaire

have been approved.

Please do not hesitate to contact me if you have any queries about this.

Yours sincerely

Gill Halstead
Research Ethics Co-ordinator, Medical Sciences

Oxford Health NHS
NHS Foundation Trust

Emma Stratful
Head of R&D
Warneford Hospital
Warneford Lane
Headington
Oxford
OX3 7JX
Tel 01865 738660
emma.stratful@oxfordhealth.nhs.uk

Our Ref: *Sponsorship_01_CoatesA_Oct 2014*

Thursday, 23rd October 2014

Miss Alice Coates
Oxford Doctoral Course in Clinical Psychology
ISIS Education Centre
Warneford Hospital
Oxford Health NHS FT OX3 7JX

Dear Ms Coates

Study Title: **Exploring Care Staff Experiences (ECSE)**

Ethics Ref: *IDREC Ref. MSD-IDREC-C1-2014-134*

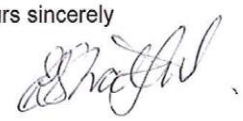
I can confirm that Oxford Health NHS Foundation Trust will act as research sponsor for the above named study, in compliance with the Department of Health Research Governance Framework guidelines. As sponsor, the Trust will provide indemnity on the understanding that your ethical approval remains in place from the Medical Sciences Inter Divisional Research Ethics Committee (MSIREC) as confirmed in a letter dated, 24th August 2014. It is noted that the study end date is 27th September 2015.

Any substantial amendment submitted to the Ethics Committee for approval must also be provided to the Trust R&D office for review as well as copies of annual reports and your final study report.

In providing sponsorship, Oxford Health NHS Foundation Trust is responsible for the conduct of the study and is required to monitor and audit a sample selection of its sponsored studies; as such your study may be subject to review by this office for compliance with the Research Governance Framework and GCP.

Finally, I would like to wish you luck with your study.

Yours sincerely



Emma Stratful
Head of R&D

cc.
Myra Cooper
Gill Halstead (MSD-IDREC Research Ethics Co-ordinator)

Appendix X: Account of Ethical Considerations

As an initial step, the researcher reviewed ethical issues teaching in order to maximise consideration of a range of possible ethical issues. Ethical issues were further discussed in meetings between the researcher and their supervisor.

At the proposal stage, particular consideration was given to the issues of consent, confidentiality, dissemination of results, managing distress and risk. These are outlined in turn below.

Approval

The research was conducted in non-NHS care homes therefore an NHS ethical opinion was not sought. Rather, ethical approval was sought from the Central University Research Ethics Committee (CUREC), University of Oxford. Further, 'Management Approval' was sought from the care homes in which the researcher was conducting the research. Sponsorship was sought from Oxford Health NHS Trust.

Consent

Care staff were provided with verbal and written information regarding the research and use of data. Consent was gained at two stages. Written consent was gained when participants completed the General Health Questionnaire-12 (Goldberg & Williams, 1988), Inventory of Geriatric Nursing Self-Efficacy (Mackenzie & Peragine, 2003) and provided demographic information. If participants did not complete the consent form but returned completed the questionnaires, it was assumed that they were providing consent; this assumption was made clear in the participant information sheet.

For participants who were invited to interview, information regarding anonymity, confidentiality and the right to withdraw were reviewed and questions regarding the process were encouraged. Written consent to be interviewed was then gained.

Given that participant's willingness to consent may vary over time, participants were given the right to withdraw from the study up at any time during interview and up to two weeks following the interview. After this time after participant's data may have been analysed and thus it would no longer be possible to remove it from the database.

Confidentiality

The limits of confidentiality were explained and agreed to prior to each interview. An example of the results of an IPA study was shown to participants in order that they had a tangible example of how their data would appear when disseminating results. In writing up the study, anonymity was enhanced by guarding against the use of lengthy excerpts and use of specific personal demographic details.

Data collection adhered to NHS confidentiality procedures. All data were anonymised and clients were given an identifier. No personal identifiers such as address were recorded. Data were stored securely in adherence with the Trust's data protection policy. Electronic data were transferred from an encrypted Dictaphone to a secure server. Electronic data files were password protected. Original questionnaires were stored securely in a lockable drawer.

Managing Distress

Given that taking part in a semi-structured interview might elicit strong emotions, all participants were reminded that they may withdraw from the study. Time was also set aside following the interview to debrief with participants.

Risk

In the instance that a participant divulged personal information regarding their mental health that suggested that they might require further support in this area, the researcher advised participants to discuss this with their GP. Should information relating to the care of residents be revealed by participants that was a cause for concern, the researcher encouraged individuals to discuss the matter with their line-manager. However, if information regarding care of residents indicated a high risk to residents, advice would be sought from the study supervisor and, if necessary from the adult safeguarding service, Oxford Health NHS trust.

Dissemination of Results

Researchers have an ethical responsibility for research findings to be accessible in order to inform the development of knowledge. As well as publishing the research in a peer-reviewed journal, a short report will be created for the research participants and the participating care homes. This will be in line with the core principles of ethical practice such as confidentiality.

References:

Goldberg D., & Williams P. (1988). *GHQ a Users Guide to the General Health Questionnaire.* Windsor: NFER-NELSON

Mackenzie, C. S., & Peragine, G. (2003). Measuring and enhancing self-efficacy among professional caregivers of individuals with dementia. *American Journal of Alzheimer's Disease and other Dementias, 18*, 291-299. doi: 10.1177/153331750301800507

Appendix Y: Table of Respondents Characteristics

	Respondents		
	Total (n = 19)	Included (n = 9)	Not Included[a] (n = 10)
Age	46.17 (13.70)	48.25 (14.30)	44.50 (13.73)
Gender	18 female	9 female	9 female
Ethnicity	13 White British (68.42%)	6 White British (66.67%)	7 White British (70%)
Length of experience in caring role	1-2 years = 3 (15.79%) 3-5 years = 2 (10.53%) 6-10 years = 3 (15.79%) >10 years = 11 (57.89%)	1-2 years = 1 (11.11%) 6-10 years = 2 (22.22%) >10 years = 6 (66.67%)	1-2 years = 2 (20%) 3-5 years = 2 (20%) 6-10 years = 1 (10%) >10 years = 5 (50%)
Highest level of qualification	None = 1 (5.23%) GCSE = 1 (5.23%) NVQ 2 = 4 (21.05%) NVQ 3 = 10 (52.63%) GCE = 1 (5.23%) BSc = 2 (10.53%)	NVQ2 = 1 (11.11%) NVQ 3 = 6 (66.67%) GCE = 1 (11.11%) BSc non-nursing = 1 (11.11%)	None = 1 (10%) GCSE = 1 (10%) NVQ 2 = 2 (30%) NVQ 3 = 4 (40%) BSc Nursing = 1 (10%)
General Health Questionnaire-12	1.73 (2.73)	0.56 (0.88)	2.8 (3.39)
Inventory of Geriatric Nursing Self-Efficacy	50.84 (11.39)	59.22 (2.86)	43.3 (10.81)**

Note. [a]Of the 10 excluded, six had a mean self-efficacy score below 6; three had a mean self-efficacy score below 6 and a GHQ score of 3 or above; One had a self-efficacy score above 6 but a GHQ-12 score above the cut-off. **An independent t-test revealed a significant difference between the self-efficacy scores of the 'Included' and 'Not included' groups (t (17)=-4.274, p=0.001).

Appendix Z: Table of Illustrative Quotes

Superordinate Theme	Selected Quotes
Feeling Torn: "Should I… take that decision?"	*"So you'd have, because she would bite you, scratch you, anything she could possibly do to get at you. So we literally had to have three of us, one to hold each arm and one to cut her nails. It sounds horrible but you had to do it because she would scratch you. And you really did not want to be scratched with those nails, you know?" (Carol, 324)* *"If someone doesn't want to drink, if someone doesn't want to eat, you can't force them. You can encourage them. You can offer goodness knows what else, but you cannot force them." (Jane, 825)* *"he doesn't like any personal care, whatsoever. And he'll make the most noise but, you know, he has to be washed and has to be dressed and yeah, but he doesn't like it at all" (Maria, 81)* *"the first time you, sort of, you're getting slapped and hit, that was the first time it ever happened, I think to myself, 'oops what have I let myself in for' but a couple of minutes later, she's happy, she's calmer than she was before, because she didn't like being dirty, but she couldn't clean herself" (Jane, 748)* *"That makes it difficult for me because I've got my own work to do as well as, so that's, it's not good when you're left, really, on your own with them… not only are you trying to do your job, keep the residents happy, you're also trying to explain everything you're doing and showing them" (Emma, 90)*

Superordinate Theme	Subordinate Theme	Selected Quotes
Togetherness and Connection	**The need for support from others: "You don't want to feel alone"**	*"for example we have a resident now that absolutely adores myself and another care assistant and it's inevitable what is going to happen... It's happened to me before where you're both like really upset or gutted but you use each other to sort of like, come on, what are playing at just get on with it and, on the other hand, you might actually sit down and actually talk about that resident and that helps because you know, you don't feel as if like, it's a big thing for somebody to go through so you don't want to feel alone and it's nice sometimes when you've got that person that you can relate with." (Emma, 780)* *"I think it'd be nice for like, someone to listen to, I know the, the nurses listen to us but they're so busy as well. They've got their own things going on, looking after residents as well. It'd be nice for someone to come on the outside and we, you know, have a, have a nice talk. Like how you've come in today, you know. I feel like I've released a lot of, you know." (Maria, 617)* *"if I want something help. They help me. They give their old notes and all everything if I want. That kind of very helpful, when we help, while we are working, and all everything, we laugh, have a laugh and all everything. Like that type of things happens, it feels easy, when we do it like this everybody get together." (Gayani, 150)* *"some of us don't have to talk, we're in a group together and you just work back to back, um, it can be lovely like that throughout the shift. It just depends who's on that shift. Um, some people can be really miserable, some people can really be lazy, some people are just slow. Um, there's a difference between being slow and being lazy" (Pauline, 333)* *"I don't find it's really hard, if we work as a team and we know how to deal with these people I don't find it is really hard. I think it's hard if there's, if you get a patient, or a dementia, who really fights, who really aggressive, I think that's difficult because you need really a strong team. A very strong team to deal with this illness" (Diwa, 571)* *"That is half the battle. You come in here and know you've got a good team, who just crack on with it. It's much easier but if people aren't, some people just don't want to do it. And you think well, why are you doing this job if you can't be bothered to do it, don't do it, but you can't come in and, you have to come in and, and do it all or nothing really. I think that's, it does, I, it does make a difference if, if you've got a bad couple of people you're working with" (Carol, 440)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	Closeness: "We are a little family"	*"it's someone else family but then because you are caring for them, you, obviously you've got that bond, there's a bond there. It is like having a child. When you have a child, obviously you've got that bond with your baby haven't you. With the residents, that what it feels like with the residents." (Maria, 232)* *"if you, are really sincere, or, how do you call that? You can, you can be attached with these people. If you really, er, how you, what is the word, you really, love your work. If you really love you work and you like your job, you know, you will be attached with these people" (Diwa, 624)* *"I just love them to bits because they're like my little family. I know I shouldn't say that but they are, because we are like one family" (Maria, 269)* *"Sometimes they light up when they see you because they know you, you become like a family, they know who you are" (Jane, 364)* *"I don't know if it's because I've like become attached to this place because I can never ever see myself working anywhere else. Because, not like against any of the care homes or anything, it's just, this is like a family and it's like going to working is like not really going to work." (Emma, 268)* *"We're all big one family. We're all big one team. But not a lot of people look at things like that. They don't see it that way, do they? You just come for the money and, pfft, that's it." (Pauline, 642)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	The value of engaging: "Their faces just beam"	*"I like to be involved in that sort of thing, you know, just go around and just being a clown really and just, you know. As long as they are laughing and they are happy it don't matter what you look like does it? Staff can look at me and pull faces, I don't care, the resident's laughing at me." (Pauline, 603)* *"her eyes, they just light up and you can see it when her husband walks in or her children, her eyes, she might not be able to talk to them, but her eyes light up and you know she knows who they are. Um, Pearl's eyes light up as well when she sees her daughter. Sometimes they light up when they see you because they know you" (Jane, 360)* *"when I've had a lovely shift and the, the residents are all round, we're having a laugh and a joke and, you've given somebody a bath and you're having a bit of a fun… chatting to them in the bath and, it's just, such a big drug." (Pauline, 376)* *"they love it. You can see their, their faces just beam, you know. Even like when we have, put music on you can see. You can see their foot tapping, see their hand going, see their head going. And you just love it, you are just watching them, you can see, you know, it's great." (Maria, 465)* *"these two were sitting and laughing and joking and even though you couldn't understand what they were talking about. But they were having this conversation and it's just like my god. It's just, how we got them to interact with each other" (Pauline, 429)*

Superordinate Theme	Subordinate Theme	Selected Quotes
Attunement	**Circularity of emotion: "I'm happy 'cause they're happy"**	*"It's nice to see them enjoying their quality of life when it is, when they are all nice and happy and happy doing things… It is nice to see them walking around, fiddling with things, enjoying life" (Jenny, 355)* *"She, she is happy when I am there and I am happy if I look after her, you know. I think that's the attachment. And if, er, some other carers don't look after her properly, I just hurt me." (Diwa, 613)* *"I know when I walk away from the residents they're happy I can go out the, the door at night time and I'm happy 'cause they're happy" (Pauline, 415)* *"I always go to her, to one resident Beryl 'oh you are coming, I like if you come, I like. If you come, I like to see you in the morning' like that. Then I feel I am doing a good job for them because they are happy about what I am doing" (Gayani, 200)* *"it is quite upsetting because you wonder if they're in pain, what's upset them." (Maria, 392)*
	Emotion as a guide to care: "It is very, very emotional for me to see somebody suffering"	*"I feel if somebody is suffering, I don't, I don't want to suffer somebody. I don't like that. I can't see. Er, that is the main quality, I want to be, er, if somebody is suffering, I always try to make him, make them comfortable." (Gayani, 250)* *"With my experience, I think I've, I can look after them and I have sympathy with these people, yeah, and then I can understand them" (Diwa,364)* *"her mouth was all dry and cracked and, you know, really smelly and nasty and that's not nice for the relatives is it?.. to me which is basic care and we didn't have anything and that made me angry" (Carol, 287)* *"the atmosphere and the noise and sometimes the mess and sometimes it can be too much for people… I recognise it if I see like another care assistant getting a little bit, like, flushed or hot and bothered and, looking stressful" (Emma, 156)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	Personal perspective-taking: "We're the one who understand them"	*"[when managing behaviour that challenges] it is probably just thinking of the other residents around, so they don't get frightened or scared of the situation, of anything that is going to happen in the situation. Because you have to think of the others around as well." (Jenny, 303)* *"you know, it is probably to do with decency. All her life she bathed herself, well, why is this person suddenly bathing me, you know." (Jane, 335)* *"we don't have to get any anger, we don't have to, you know get, we must be patient with them. We don't have to get angry or whatever, er, because they don't know completely, they don't know what they do. They are not going to harm us or anything." (Gayani, 304)* *"You want to know, you want to sit down and know how you can help them, you know" (Maria, 393)* *"you could say to them as well, is there anything that is troubling you? Why's this come about? Is there a problem? There might be something underlining it, why it arose. You can try and sort out what the problem is" (Jenny, 315)* *"sometimes they, they shout at you. So you have to think why this lady shout. I think, is she in pain? Is she hungry? Or you have to know what, why, what's the reason for this" (Diwa, 389)* *"Um, but some people you see, wherever you work, they just go in there, personal care, pfft, and if somebody's like challenging like that, they sort of like go in with their attitude, um, they go in, they go in with an attitude and obviously that's going to make the person even more angry or challenging or upset" (Pauline, 100)* *"When he says 'stop', just stop for a minute and that's it. Because when you carry on, that's when he start get angry and show you really his fists and most, I think there is quite a few people he really punch. He punches carers because they don't understand him. They just rush him and pull the bed linen straight away without communicating, you know asking them." (Diwa, 133)* *"Some people will say, I don't know why we're doing this and doing that because they don't understand and it's like, well, at the end of the day, they are a human being still, you've still got to talk to them as normal. Um, sit and talk to them and given them more one to one, um." (Pauline, 262)*

Superordinate Theme	Subordinate Theme	Selected Quotes
		"So, some are still are, can have a conversation with you and some can't. So you have to try and work out what they are feeling while you are caring with them. Um, you are trying to explain to them what you are doing as you are doing it but you don't know if they actually can hear or understand what you are saying so sometimes they get upset because they don't understand fully what you have said" (Jenny, 51) *"I'd rather he didn't, um, know that he'd hit me in the face because then that's, it doesn't make him feel bad" (Emma, 372).*

Superordinate Theme	Subordinate Theme	Selected Quotes
Caring as Part of Life: "this is more than a job"		*"some of these people, I think they just come here for, I am not saying just for the money, because you can see on television what they, how they deal with these people isn't it? It's terrible. So I think, some of these people, they only come here just to earn money, just to get the money but not looking after these people properly." (Diwa, 282)*
	Caring is part of my identity: "It is in my blood"	*"I think god has given me patience. I am not making up. It's, I don't feel any, er, any what kind, how can I explain... er, it, er, it automatically it comes to me." (Gayani, 295)* *"I took it and I thought to meself from the very first day, I have loved the job… it is like that's where I was meant to be" (Jane, 75)* *"I care 24/7 anyway at home because my husband is disabled. So I think having that side of caring as well as being here. I sort of get, with my husband being disabled and the elderly, I think that is why as well I have stayed. Because I deal mostly in care a lot. So I think that is why I am quite into it." (Jenny, 454)* *"Things like, I don't, things that I hear, especially from my residents from back in their day and it's like, it makes you have a different perspective on life. People my age don't understand what I am talking about half the time and it's like because things have been said to me at work, I take that home and that then becomes a part of me like" (Emma, 604)* *"I am 67 nearly so you, you've seen a lot of life, haven't you, you've seen, you've had two children, you've got grandchildren, you've done that, so you've been through the whole gambit of caring if you like, you know, the stroppy teenager daughters and all the rest of it so, and I think as you get older you, you do gain more experience." (Carol, 212)* *"As for me, because of my experience, I er, is I can understand now. Also, with my age now, you can understand how to be old. Do you know what I mean? And I, I know what, why, why are, why they are like this, why. Getting older is not easy. It's hard, they are lonely, you know" (Diwa, 378)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	Acceptance: "Every day is a new day"	*"But, there are days when you don't get smiley faces. Not every day is a good day but, you just work with what you have got and if somebody's in a foul mood, they're in a foul mood. Try and cheer them up. If it doesn't work move on to the next thing. Just all you've got to do is try, try your hardest and if, and even if somebody else comes along and, they make them happy then fair enough" (Emma, 725)* *"whether you're getting hit or not, whether you're getting cuddles, because you get loads of cuddles in this" (Jane, 515)* *"every day is a new day isn't it? And you've just got to look at the positives and you know, what you can do different, like, what haven't you had for a little while" (Pauline, 598)* *"these people are getting older, you cannot expect, you know, they're getting better" (Diwa, 351)* *"But you just have to go with the flow really. Obviously you don't want to be punched or kicked but it happens, it does happen. It's not nice" (Carol, 348)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	A genuine interest in others: "They've all got amazing stories"	*"I feel that they are really nice people to know but some of them do have their little quirks and that that you find out about them, like about their jobs, what they used to do, some were in the war. Some were at d-day landings. So whenever that time comes up you can talk about it with them. And that can bring back all memories for them. They love it, they love to talk about it." (Jenny, 210)* *"They just see an old lady who's incontinent or awkward or nasty and they don't see the bigger picture sometimes. That everybody was somebody's mum, somebody's dad and I think sometimes that that sort of gets forgotten and, we're all guilty of that I think but it, it is a shame that you, you forget that those people had a life basically before and now they haven't" (Carol, 111)* *"so whatever you do, it's, you have to learn about your resident. You, if you just start the job, don't go in thinking you know, say you've just started, you could have worked in another home. Don't go in thinking that everyone that, where you worked before is going to be exactly the same as where you are working now 'cause they are not, everyone's different, you're different, I'm different, your colleagues are different, your, one tutor's different to another tutor, everyone's different, so you learn about the resident." (Jane, 781)* *"I'm not here for the money, that's my second bit. It doesn't matter what rate I'm on, doesn't matter. I'm here for the residents and I will do my best for those residents." (Pauline, 359)*

Superordinate Theme	Subordinate Theme	Selected Quotes
	The motivation to care: "It's like a drug and I get a kick out if it"	*"you're doing more and more and more like… say I had a lot of problems this morning with residents, and I couldn't get them to do what I wanted them to do or etcetera, um, I come in tomorrow and go another way around it, differently" (Pauline, 385)* *"It can be very... demanding but, challenging but I enjoy it. I enjoy my job. I enjoy working here." (Maria, 25)* *"You need to want to be caring for the residents and wanting to do the care job... to come to do, to be in a care home really. I think that is one of the main qualities you need to have." (Jenny, 412)* *"That is what we are here for. You know, it is not for the money, Of course it's part of it, but that is what we are here for, to look after these old people, because no one is going to look after them, it is us" (Diwa, 405)* *"I can normally work round somebody like that which I love doing things like that as a challenge because to me it's a very good challenge" (Pauline, 113)* *"I get a kick out of it. It, it's like, um, like a big reward" (Pauline, 375)* *"I just feel really satisfied. I've done my job properly, they are all happy." "I know that I've done everything that I should have done and everything that I can do, so yeah, I do feel satisfied" (Emma, 720)* *"I am very satisfied what I am doing. I can be happy all the day and end of the day I am happy. I did something for somebody" (Gayani, 546)*

Appendix AA: Submission Guidelines for Proposed Journal

Dementia: The International Journal of Social Research and Practice

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

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2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

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3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the **'Online Help'** button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted by email to Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor Dementia, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

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4. Journal contributor's publishing agreement

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. For more information please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we

reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

4.1 SAGE Choice and Open Access

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE *Choice*, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE *Choice*. To check journal eligibility and the publication fee, please visit SAGE Choice. For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit SAGE Publishing Policies on our Journal Author Gateway.

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5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of *Dementia* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the SAGE Journal Author Gateway.

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6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at http://icmje.org. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (http:/www.wma.net) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (http:/www.cioms.ch). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

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7. Acknowledgements

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

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

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit Funding Acknowledgement on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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8. Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. Click here to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.
Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

9.3 Reference Style

Dementia adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how

best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online. The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

9.4.4 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's Guidelines for Authors on Supplemental Files.

9.4.5 English Language Editing services

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit English Language Editing Services for further information.

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10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

10.2 E-Prints

SAGE provides authors with access to a PDF of their final article. For further information please visit http://www.sagepub.co.uk/authors/journal/reprint.sp.

10.3 SAGE Production

At SAGE we work to the highest production standards. We attach great importance to our quality service levels in copy-editing, typesetting, printing, and online publication

(http://online.sagepub.com/). We also seek to uphold excellent author relations throughout the publication process.

We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Dementia* with SAGE.

10.4 OnlineFirst Publication

Dementia offers OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our OnlineFirst Fact Sheet.

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at dem.pra@sagepub.com.

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