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Doctoral Thesis

Challenging Behaviours: Caregiver Attributions and Emotional Experiences

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Statement of Word Count for Thesis Sections

	Text	References/ Tables/ Appendices	Total
Thesis Abstract	266	-	266
Literature Review	6,715	6,136	12,851
Research Paper	7,999	2,616	10,615
Critical Appraisal	3,521	408	3,929
Ethics Proposal	1,874	3,859	5,733
TOTALS	**20,375**	**13,019**	**33,394**

Abstract

Reasons why people might behave in ways that are challenging for others include dementia and learning disabilities. The ways in which caregivers, who may be family members or staff, make sense of the causes of these behaviours can affect how they respond to the person. Additionally, challenging behaviours can have an emotional impact on caregivers, which may affect the attributions they make about the behaviours. A systematic literature review was conducted to identify factors which are related to the causal attributions carers make about challenging behaviours. Sixteen quantitative studies that had examined carer attributions in the areas of learning disabilities and dementia care were reviewed. A wide range of factors had been examined in relation to attributions, which were grouped for comparison into: carer and individual demographics, individual's level of impairment and type/ severity of behaviour, service and environmental factors and carer emotions. Some factors were identified as being associated with carer attributions, including the level of impairment of the individual and the type of challenging behaviour. A qualitative research project was conducted: nine direct care staff in a residential dementia care setting took part in individual semi-structured interviews about their emotional experiences of working with challenging behaviours. Interpretative phenomenological analysis was used to analyse the data, and three broad themes were constructed: "They don't know what they're doing": Understanding causal attributions; "It's knowing them as people": Getting to know people with dementia; and "That's part of the job": Experiences of the role of care staff. These themes were discussed with reference to the literature, and clinical implications and directions for future research were proposed.

Declaration

This thesis presents research submitted in partial fulfilment of the requirements for the

Doctorate in Clinical Psychology at Lancaster University.

The work presented in this thesis is my own, except where stated otherwise. This research

has not been submitted for any other academic award.

Helen Lewthwaite

Signed …………………………….

Date……………..............................

Acknowledgements

Firstly I would like to thank my participants for giving their time and sharing their experiences with me, and their managers for supporting this. This research project would not have been possible without them.

I am grateful to my field supervisor Bev for her guidance, encouragement and help with recruitment. I would like to extend thanks to my research supervisor Jane for her expertise and support throughout the research process.

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Section One: Literature Review

What are the factors associated with caregiver attributions of challenging behaviour? A

systematic review

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Abstract

Objectives

Individuals who care for people with challenging behaviours make attributions about the causes of behaviours, which can affect their response to the person in their care. A number of factors may be associated with differences in the attributions caregivers make about challenging behaviours.

Method

A systematic search of three major databases using specified key words concluded with a total of sixteen studies. Studies were included if they were written in English and had used a quantitative methodology to examine one or more factors in relation to carer attributions of challenging behaviour.

Results

The reviewed studies included staff and family carers of people with learning disabilities and in the area of dementia care. Factors that had been examined in relation to caregiver attributions were grouped for comparison into: carer and individual demographics, individual's level of impairment and type/ severity of behaviour, service and environmental factors and carer emotions.

Conclusions

The wide range of factors examined meant few clear conclusions could be reached; however, clinical implications and directions for future research are discussed.

Practitioner Points

      Positive clinical implications

- Working in an environment with high cognitive demand may be associated with

  differences in the attributions staff make about challenging behaviours.

- Environmental restrictions may be associated with more stable attributions of behaviour.

      Limitations of the study

- The results of this review are most relevant to staff working with people with learning

  disabilities as this is the area the majority of the reviewed studies were conducted in.

- Six of the reviewed studies were conducted with vignettes, which may not accurately

  represent the carers' true responses to challenging behaviours.

Introduction

Challenging behaviours, or behaviours that challenge, are most often described as actions by a person that negatively impact on that person's wellbeing as a result of the distress they cause; this distress may be physical or psychological (James, 2011). These behaviours are challenging for staff or family caring for the person, though the person themselves may not consider them a problem, for example wandering in dementia does not necessarily result in the person being in danger (Wigg, 2010). Challenging behaviour is widely understood to be functional for the individual and to be shaped by the impact it has on the person's environment (Emerson, 1995). For example, self-injury might be positively reinforced when staff intervene to stop the behaviour and by so doing pay attention to the person, which may be a desirable outcome for the individual (Hall & Oliver, 1992).

Other examples of challenging behaviour include verbal and physical aggression and sexually inappropriate behaviour (James, 2011). Some challenging behaviours carry a potential risk either to the person themselves or to those around them, which may include family members, fellow residents or care staff. The term challenging behaviour is often applied to particular groups of individuals such as those who have learning disabilities (Whittington & Burns, 2005), dementia (Opie, Doyle & O'Connor, 2002), and acquired brain injuries (Rahman, Oliver & Alderman, 2010). It is worth noting that in these and other contexts the same behaviours might not be given the same description, for example in dementia care some researchers refer to "behavioural disturbance" instead of challenging behaviours (Martin-Cook, Remakel-Davis, Svetlik, Hynan & Weiner, 2003). Definitions of challenging behaviour include the following by Emerson (1995):

> Culturally abnormal behaviour, of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or

behaviour which is likely to seriously limit use of, or result in the person being denied

access to, ordinary community facilities.

While this definition was written to describe challenging behaviour in people with learning

disabilities, it could just as easily be describing challenging behaviour by someone with

dementia (James, 2011). While it is acknowledged that there may be differences in the

experiences and behaviour of people with different difficulties such as dementia, learning

disabilities and brain injuries, it seems that the term "challenging behaviour" is defined and

used in the same way in different contexts. Therefore this paper will not limit consideration

of challenging behaviour to only that associated with one cause.

The individuals most often required to respond to and attempt to manage challenging

behaviours are informal family carers or paid support staff. The term "carer" or "caregiver"

is frequently used to identify these groups of people, however it has been argued that this is a

term with which many people in these roles do not identify (Molyneux, Butchard, Simpson &

Murray, 2011). However, most of the published research pertaining to people who can

present with challenging behaviours does use these terms to describe support staff and family

members who offer significant support. Consequently, while the criticisms of the term are

acknowledged, the term "carer" will be used in this paper to refer to people in these roles.

The ways in which carers respond to and manage challenging behaviours have been

shown to have an effect on the level of distress experienced by the individual presenting with

the behaviour (Griffith, Hutchinson & Hastings, 2013). Moreover, carers' beliefs and

feelings about challenging behaviours are likely to influence how they respond to the people

for whom they provide care (Hastings & Remington, 1995). A number of theoretical

approaches have been developed to make sense of how we understand behaviour and the

emotional consequences of this. One of these, attribution theory, studies the way in which

people perceive the causes of behaviour. Attribution theory has become a widely used

framework applied to a range of settings and individuals. A key assumption of this approach is that a situation does not directly lead to a reaction; rather cognitions have a mediating role (Heider, 1958). In effect, how individuals perceive, understand and recall events will affect how they react, including their emotional reactions (Försterling, 2001).

When making attributions, a number of dimensions have been proposed on which the causes of behaviours can be understood. The cause of a behaviour can be perceived to lie within the person doing the behaviour (internal attribution), or within the environment (external attribution) (Försterling, 2001). The cause can also be considered to be stable or unstable, which relates to whether the cause is expected to change over time (unstable) or not (stable) (Heider, 1958). A further dimension of causality is that of controllability, which refers to whether an individual is perceived to have control over an event or behaviour (Weiner, 1995). Behaviours can be understood as personal, where there is something unique to the individual that causes the behaviour, or universal, where most people would act that way in the same situation. Finally, behaviours can be considered to be global or specific, with global causes leading to wider effects (Stratton, Munton, Hanks, Heard & Davidson, 1988).

Weiner (1980) developed attribution theory further by proposing his model of helping behaviour, in which when an event (or behaviour) occurs, individuals make attributions about the cause. These attributions, along with associated emotional reactions, can determine the person's emotional and behavioural response. This model of helping behaviour has been suggested to apply to staff responses to challenging behaviour (Dagnan, Trower & Smith, 1998). It places importance on the role of emotions in determining response, for example if a member of staff understands the cause of a behaviour as internal, controllable and stable, they may be more likely to feel angry and have less belief that the person's behaviour could change (Rose & Rose, 2005; Stanley & Standen, 2000). Dagnan et al. (1998) found support

for the role of the model of helping behaviour in staff responses to people with learning

disabilities and challenging behaviour, with links found between attributions of control, staff

negative emotions, and reduced willingness to help from staff.

However, more recently it has been proposed that Weiner's model is unable to

consider the complex range of influences of relevance to responses to challenging behaviour

(Cudré-Mauroux, 2010). For example, staff can hold multiple perspectives about a person's

behaviour (Jahoda & Wanless, 2005) and several different attributions may be made during a

single encounter with one episode of challenging behaviour. Moreover, these attributions

may even be contradictory and influenced by a variety of factors (Cudré-Mauroux, 2010).

The theories described above have been related to the responses of both formal paid

carers and informal family carers to challenging behaviours. It is acknowledged that there

will be differences in the perspectives of a family carer compared to a member of staff

(Cohen-Mansfield, Golander & Heinik, 2013). Family carers will have some form of

additional relationship with the person and there may be differences in perspectives between,

for example, spouses and adult children (Broese van Groenou, de Boer & Iedema, 2013).

However, it can be considered that there are many similarities. Whether someone is a formal

or informal carer, they will be required to carry out many of the same tasks, including

supporting the person to move around, personal care, support with meals and drinks and

managing their medication. If the person behaves in a way that is challenging then whether

the carer is paid or a family member they are responding to the same situation. Therefore for

the purposes of this review paid carers and informal carers can be considered together.

Factors that have been proposed to affect the attributions made by carers and staff

about challenging behaviour include those relating to the cognitive ability level of the person

displaying the behaviour (Tynan & Allen, 2002), the type of behaviour (Dilworth, Phillips &

Rose, 2011) and the emotional wellbeing of the carer (Cook, Ahrens & Pearson, 1995; Rose & Rose, 2005).

In one of the few reviews in this area, Lambrechts, Petry and Maes (2008) conducted a review of staff factors that influence responses to people with learning disabilities and challenging behaviour. They found that staff often considered the cause of challenging behaviour to be internal to the person, and that behaviours by a person that caused damage to the environment were experienced as more challenging than self-directed behaviours by the individual (Lambrechts et al., 2008). The findings of the review were difficult for the authors to synthesise, partly as they included both quantitative and qualitative studies with a range of methodologies, suggesting that a review which focussed on a narrower range of methodologies may be useful.

As there is not yet a sufficient body of published qualitative research examining the experiences of attributions of challenging behaviour to conduct a meta-synthesis, a review focussing on quantitative studies appears more relevant at this time. To date, no reviews examining factors related to attributions for causes of challenging behaviour other than learning disabilities, such as dementia and brain injuries, have been identified.

Consequently, in order to further understanding of what determines the responses of caregivers to challenging behaviours, the aim of this paper was to conduct a systematic review of the quantitative research pertaining to the study of factors that may be related to carer attributions about challenging behaviour. The research question was: What factors will be found to be related to the attributions caregivers make about challenging behaviours?

Method

Search Procedure

An electronic search was conducted in April 2015 using the academic databases PsycINFO, Web of Science and CINAHL. The search terms used were: "attribution* AND behavi* AND (staff or care*)". These terms were used in free text searches in each database. The search was limited to articles published in the English language. The term "behavi*" was used without specifying that behaviours be "challenging" to account for the use of different terms or reference to specific behaviours such as aggression in the published literature.

Figure 1 summarises the process by which studies were identified for inclusion in the review. The above searches yielded 2104 articles across the databases, which was reduced to 1771 following the removal of duplicates from the search results. This systematic search did not reveal any existing systematic reviews on the topic. 1433 studies were eliminated as their titles made it clear that they were not relevant to the topic area; this left 338 articles. The abstracts of these papers were reviewed in order to assess the studies against the inclusion criteria (see below). When the relevance of an article was unclear from the abstract, the method and results sections were also reviewed. Reference lists of the studies that met the inclusion criteria were reviewed for any additional articles that may have not been identified through the primary search procedure; no further articles were identified by this means however. Sixteen studies were identified that fit the inclusion criteria and were included in this systematic review.

--Insert Figure 1 here--

Inclusion Criteria

Studies published prior to March 2015 were reviewed to assess their eligibility for inclusion in the systematic review. No other limit was set on date of publication. Studies were included if they were published in a peer-reviewed journal and had used a quantitative methodology to examine the relationship of one or more factors to carer attributions of challenging behaviour. Relevant factors included any concrete, measurable factor that could be related to carers' attributions about the challenging behaviours of people for whom they provided care.

Studies were eligible for inclusion if they had looked at carers of adults with challenging behaviour. No further limitation was placed on the participant group. "Carers" included informal family carers and paid staff, but excluded studies that had used as participants people who were not carers, for example students. Studies that had used vignettes to measure carers' responses to challenging behaviour were eligible for inclusion. It was considered that participants who were carers would draw on their caring experiences when faced with the vignette and therefore would be accessing similar responses to those they would have to challenging behaviours in their caring role.

Individuals with challenging behaviour included adults whose conditions are not considered episodic in nature; this therefore excluded challenging behaviours associated with mental health diagnoses such as schizophrenia but included people with learning disabilities, dementia or acquired brain injuries and challenging behaviours. This limited the causes of challenging behaviour to those which are associated with some level of cognitive impairment from which the person would not be expected to recover.

As this was not a lifespan approach to the study of factors related to attributions studies that had as participants carers of children were not eligible for inclusion. It was considered that carers of children would have additional roles to that of carer, such as

providing education and discipline, that would lead to differences in responses to behaviours. Where a study included carers of adults and children, the study was included where the majority of individuals would have been adults. For example, Lambrechts, Kuppens and Maes (2009) included staff of clients aged 8 to 70 years. However, the mean age of this client group was 36 with a standard deviation of 15, meaning that assuming a normal distribution of client ages a large majority of clients would have been above the age of 21 (one standard deviation below the mean), and therefore the study was included in the review.

As much of the research in this area has been analysed using bivariate correlations, studies that had looked at the impact of attributions on another factor could also be eligible for inclusion. This is because correlative relationships between variables are simply associations, not evidence that either variable directly causes the other, or in which direction any causality lies. Additionally, some studies which had used multiple regressions with attributions as the predictor variable may have run bivariate correlations before their main analysis. For example, Cook et al. (1995) were interested in the effect of carer attributions on carer depression. The authors used a multiple regression analysis to study this relationship which as it used attributions as the predictor variable was not included in this review. However, part of their analyses involved running bivariate correlational analyses between attributions and duration of caregiving, which meant that this aspect of the study was eligible for inclusion in this review.

Results

Study Characteristics

Table 1 provides an overview of the 16 studies included in this review, listed in alphabetical order by first author. The sample sizes in the reviewed studies ranged from 14 to 160 ($M = 69.75$). Of the 16 reviewed studies, only one (Parker, Clarke, Moniz-Cook &

Gardiner, 2012) determined their optimum sample size using a prospective power calculation, though their final sample size did not meet this requirement. One other study (Rose & Rose, 2005) did also address the issue of the appropriateness of their sample size, though did so by referring to recommendations made by other authors rather than by a study specific power calculation.

Twelve of the sixteen reviewed studies were carried out in the United Kingdom. Two were conducted in the United States of America (Cook et al., 1995; Martin-Cook et al. 2003), one in the Netherlands (Zijlmans, Embregts, Bosman & Willems, 2012) and one in Belgium (Lambrechts et al., 2009).

-- Insert Table 1 here--

Settings

Ten of the studies looked at challenging behaviour associated with people who had learning disabilities, four were carried out in the field of dementia care, one across several areas of care for older people including dementia, and one did not state the cause of challenging behaviour (see Table 1). Ten of the studies recruited participants who were staff working in a direct caring role with people with learning disabilities. In relation to the studies where care for older people was the context, two studies focussed on staff and three had family members who cared for people with dementia as participants. The study that did not state a cause of challenging behaviour recruited staff. No studies involved family members caring for people with learning disabilities.

Participants

Twelve of the reviewed studies reported the genders of their participants. A further study (Dagnan, Grant & McDonnell, 2004) reported data for their large participant group but not specifically for the smaller group who were included in the analysis that was relevant to this review. Of those that reported gender data, all studies had a greater number of female participants compared to male. Tynan and Allen (2002) reported percentages of female participants in the two conditions separately and it was not possible to calculate the numbers of male and female participants from this information. Therefore numbers of female and male participants were available for ten of the reviewed studies (see Table 1).

Five of the reviewed studies did not report any data for the ages of their participants. Dagnan et al. (2004) again reported data for their large participant group only, so for the purpose of this review the data are not known. Of the remaining ten studies, five reported means and standard deviations only. One study reported only that 90% of participants were between the ages of 21 and 45. Therefore four of the fourteen reviewed studies reported a range for participant ages; the youngest participant reported was aged 18 years and the eldest 66 years in these four studies.

Only three of the fourteen reviewed studies did not refer to participants' length of experience in their caring role (Dagnan et al., 2004; Martin-Cook et al., 2003; Weigel, Langdon, Collins & O'Brien, 2006). One study (Kleinberg & Scior, 2014) simply stated in their inclusion criteria that in order to take part participants must have at least two months' experience but did not report more specific data for their participants. A number of studies reported an average and standard deviation only, while some reported a range. The lowest value reported was 0 years, and the highest 387 months (32.25 years). For details, see Table 1.

Two groups of studies had an author in common: Dagnan et al., 2004 and Hill and Dagnan, 2002; and Dilworth et al., 2011, Mills and Rose, 2011 and Rose and Rose, 2005. However these studies all used different groups of participants.

Measures

The majority of the reviewed studies asked participants to think of real examples of challenging behaviours by the individuals they supported or cared for when taking part in the study. Six of the studies used vignettes to measure attributions instead of the participants' own experiences (Hill & Dagnan, 2002; Kleinberg & Scior, 2014; Parker et al., 2012; Snow et al., 2007; Stanley & Standen, 2000; Tynan & Allen, 2002).

As can be seen from Table 1, the reviewed studies used a wide range of measures. This was largely due to the variety of factors that were studied in relation to attributions of challenging behaviour. All of the measures used by the reviewed studies are listed in Table 1.

All studies included a measure of carer attributions, however only four attribution measures were used by more than one study, and no measure was used by more than three studies. The measures used by more than one study were the Challenging Behaviour Attribution Scale, the Controllability Beliefs Scale, the Leeds Attributional Coding System and the Attributional Style Questionnaire. These are all validated self-report measures (Dagnan, Hull & McDonnell, 2013; Hastings, 1997; Peterson et al., 1982; Snow et al., 2007). All the measures of attributions used were self-report measures, with the exception of the Leeds Attributional Coding System, which involved the researchers coding interview data and applying the measure (Tarrier et al., 2002). While most of the attribution scales used elicit scores for more than one dimension of attribution, two studies used the Controllability

Beliefs Scale (Dagnan et al., 2004; Dilworth et al., 2011; Mills & Rose, 2011), which looks at participants' perceptions of the individual's control over their own behaviour only.

Data Analysis

Where studies have included a number of variables and run multiple analyses, only those that were relevant to the research question of this review have been reported. For example, Lambrechts et al. (2009) ran a set of bivariate correlations between type of challenging behaviour, type of intervention, staff emotional reactions and attributions. However, only the correlational analyses between attributions and the other factors have been reported in this review. Analyses from the reviewed papers are detailed in Table 1.

All of the reviewed studies used quantitative statistical tests to analyse their data. Most of these were parametric analyses, however six studies (Dilworth et al., 2011; Mills & Rose, 2011; Snow et al., 2007; Tarrier et al., 2002; Tynan & Allen, 2002; Weigel et al., 2006) used non-parametric tests. Two of these studies (Dilworth et al., 2011; Tarrier et al., 2002) used a mixture of parametric and non-parametric tests, while the others used non-parametric tests only. Four of these studies (Dilworth et al. 2011; Mills & Rose, 2011; Snow et al., 2007; Tarrier et al., 2002), gave a clear rationale for the use of non-parametric tests. Tynan & Allen (2002) and Weigel et al. (2002) did not give a rationale for their use of non-parametric tests, however this was thought to have been due to their data measurement being based on the use of rating scales which may not have met parametric assumptions.   Snow et al.'s (2007) data were derived from a frequency count of attributions and therefore did not meet parametric assumptions. Mills and Rose (2011) identified that the majority of their variables were not normally distributed and so used non-parametric tests. Dilworth et al. (2011) identified that only two variables were normally distributed, for those that were not normally distributed they used non-parametric analyses. Tarrier et al. (2002) also used both parametric

and non-parametric tests, depending on whether the data for each variable were normally distributed.

Five of the reviewed studies reported the use of tests to determine if their data met assumptions underpinning parametric tests (Dilworth et al., 2011; Kleinberg & Scior, 2014; Parker et al., 2012; Rose & Rose, 2005; Tarrier et al., 2002). Of the fourteen studies that used parametric tests of relevance to the research questions of this review, eleven ran correlations, four used *t* tests, four used ANOVAs (with post-hoc tests where appropriate), and one used linear regressions. One study (Tarrier et al., 2002) reported using a higher minimum acceptable level of significance due to multiple comparisons being run; while the reason for this was not clearly stated it is assumed that it was to reduce the risk of Type 1 errors.

Quality Assessment

The administration of a quality assessment tool was not used as an inclusion criterion in this review. However, the included studies were evaluated against a quality assessment tool to consider the relative strengths and weaknesses of their methodologies. The quality assessment measure used was the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (von Elm et al., 2007). See Appendix A for the checklist used. Table 2 shows, for each reviewed study, which of the numbered items on the STROBE checklist were met. Some items contained more than one criterion and therefore have a possible score of greater than one; the possible scores for each item are included in the table. Each study was allocated a total score on this basis.

-- Insert Table 2 here --

As can be seen from Table 2, the maximum score on the quality assessment tool was 26. The scores of the reviewed studies ranged from 17 to 25 (*M*=22.06).

Findings

While the studies included in this review assessed a number of different factors and their relationships to carer attributions, these factors are grouped here for ease of comparison. The groups of factors are: carer and individual demographics, the individual's level of impairment and type/ severity of behaviour, service and environmental factors, and carer emotions.

Carer and individual demographics

Six studies examined demographic factors such as gender, age and length of experience in a caring role (Cook et al, 1995; Dilworth et al., 2011; Kleinberg & Scior, 2014; Parker et al., 2012; Snow et al., 2007; Tarrier et al., 2002). All six looked at carers' duration of experience in this role; Tarrier et al. (2002) included duration of dementia, but as the study was conducted with family caregivers this figure was included as duration of caregiving. Four of these six studies found no significant relationship between length of time in role and attributions. Cook et al. (1995) found that carers made more stable and global attributions the longer they had been in a caregiving role, meaning carers believed the care recipient's behaviours to be less subject to change and affecting more aspects of their life the longer the carers had been in post. However this association was quite weak, with a correlation coefficient (*r*) of 0.25. Snow et al. (2007) found no correlation between attributions and time participants had worked with people with learning disabilities, but they did find that the longer participants had worked with people with self-injurious behaviour, the more they believed that behaviours were due to causes within the individual and subject to change.

These were medium correlations, with Spearman's Rank correlation coefficients (ρ) of 0.40 and 0.35 respectively.

No correlation was found between attributions and staff age (Dilworth et al., 2011; Snow et al., 2007), or the age of individuals with dementia (Tarrier et al., 2002). Two studies included staff gender in their analyses: neither found a difference in attributions relating to carers' gender (Dilworth et al., 2011; Kleinberg & Scior, 2014) or to the gender of individuals with learning disabilities (Kleinberg & Scior, 2014).

Individual's level of impairment and type/ severity of behaviours

Of the three studies which examined attributions of control in relation to care recipients' level of impairment, two found significant effects, with individuals who were less impaired considered to have more control over their behaviours (Stanley & Standen, 2000; Tynan & Allen, 2002). In contrast, one found no significant correlation between these variables (Dilworth et al., 2011). Increasing dementia severity and impairment was found to be correlated with beliefs that behaviours were more likely to change over time and with the carer holding beliefs that the cause of the behaviour lay within themselves rather than within the individual who was behaving in a way that was challenging (Tarrier et al., 2002). However, these associations were quite weak, with correlation coefficients (r) of 0.20 and 0.24 respectively.

Two studies examined topography of behaviour (Stanley & Standen, 2000; Zijlmamns et al., 2012). One found that staff attributed greater control to aggressive behaviours compared to self-injury, and greater stability to self-injury compared to aggression or destructiveness (Stanley & Standen, 2000). Zijlmans et al. (2012) found that staff attributed greater levels of controllability to clients whose behaviour was directed at their environment,

or their environment and themselves, than if it was solely directed at themselves (no effect was found of type of behaviour on attributions of stability) (Zijlmans et al., 2012).

Service and environmental factors

Five studies examined service level or environmental factors. An environment that placed a greater level of cognitive demand on staff by requiring them to attend to other tasks was found to lead to more internal attributions for aggressive behaviour, and greater attributions of control for non-aggressive behaviour (Parker et al, 2012). Rose and Rose (2005) found no difference in attributions between staff working in high challenging behaviour contexts compared to low challenging behaviour environments. No impact was found of number of hours worked or shift pattern on attributions (Dilworth et al., 2011). There was a negative correlation between attributions of control and the level of functioning of the organisation (Dilworth et al., 2011), however training staff had received did not predict attributions (Kleinberg & Scior, 2014). The type of intervention used to manage challenging behaviour was found to be associated with differences in the attributions made by carers about the behaviour (Lambrechts et al., 2009). Namely, a correlation was found between environmental restrictions such as tying the individual to their bed or locking doors and windows as a response to behaviour and believing that the behaviour would not change over time. Additionally, an association was found between positive or alternative interventions such as distraction and attributions that the person was in control of their behaviours (Lambrechts et al., 2009).

Carer emotions

Finally, eight studies examined the relationship between carer emotional wellbeing or coping and attributions. In relation to carer distress, Martin-Cook et al. (2003) found a

correlation between attributions of control and caregiver depression and resentment. The

correlation between resentment and the belief that behaviours are under the person's control

in particular was a strong one ($r = 0.72$), meaning that the more carers believed the person to

be in control of their behaviours, the greater level of resentment they felt about their role as

carer for that person. Tarrier et al. (2002) found no correlation between carer distress and

attributions, however did find that increased carer strain was related to beliefs that behaviours

were due to causes more personal to and controllable by the individual. Snow et al. (2007)

found a negative correlation between the emotional exhaustion sub-scale of the burnout

inventory and the frequency of stable attributions made about challenging behaviours,

meaning that carers who were more emotionally exhausted believed the person's behaviours

to be more likely to change. This was a moderate association ($\rho = 0.3$). Two other studies

found no correlation between staff stress or burnout and attributions (Mills & Rose, 2011;

Parker et al., 2012).

Two studies examined carer coping styles. Hill and Dagnan (2002) found no

correlation between attributions and wishful thinking or practical coping styles. Dagnan et al.

(2004) found that attributions of control were associated with carers having a wishful

thinking (emotion focussed) coping style, but not a problem solving focussed coping style.

However on the quality assessment checklist the study by Dagnan et al. (2004) attained the

lowest score of the reviewed studies (17), losing marks by for example not providing

sufficient information about their participant group, not describing any efforts to reduce

sources of potential bias, and not discussing the limitations of their analysis. This low quality

score may reduce the reliability of their results.

Two studies included a measure of carers' expressed emotion (Tarrier et al., 2002;

Weigel et al., 2006). Expressed emotion is measured as the degree of criticism, hostility,

emotional over-involvement, warmth and positive comments made by a person (carer) when

discussing their relationship with an individual (care recipient) (Brown, 1985). Both Tarrier et al. (2002) and Weigel et al. (2006) found that carers with high expressed emotion were more likely to attribute challenging behaviour as being internal to and controllable by the individual. Tarrier et al. (2002) also found that carers who were more highly emotionally overinvolved made attributions that were more external to the care recipients and internal to themselves (the carer).

Discussion

The studies included in this review examined a wide range of variables in relation to attributions that carers make about challenging behaviours, many of which were included by only one or two of the reviewed studies. However, some key findings can be concluded from the review process. One was that the length of time in a caring role was not found to correlate with the attributions made by most studies and where an association was found this was quite weak. Gender and age were not correlated with attributions made by carers. There was some evidence that the severity of impairment in people with either dementia or a learning disability was associated with differences in the type of attributions carers make. Individuals who were less cognitively impaired were believed to be more in control of their behaviours. There appeared to be little evidence for carer stress impacting on attributions, with two studies finding no association and a third reporting a weak correlation only. Carers with higher expressed emotion appear to be more likely to believe challenging behaviours to be due to causes within the person for whom they were caring, and under the individual's control.

Several issues limit the generalisability of the findings of this review. All but two of the studies identified to fit the inclusion criteria had been carried out with carers of people with learning disabilities or dementia. One of the exceptions was carried out with carers of

older people with challenging behaviour, which included people with dementia, and the other did not state the client group but was thought to have been carried out with staff working with people with learning disabilities. This distribution reflects the published research on challenging behaviour, which is focussed primarily on learning disabilities, with some research in dementia and less in other areas, for example acquired brain injuries. Some research does not refer to "challenging behaviour" but rather to individual behaviours such as aggression or self-injury. This was taken into account when designing the search terms for the current review and several of the reviewed studies did not use the term "challenging behaviour", for example Kleinberg & Scior (2014) referred to "aggressive behaviour", Martin-Cook et al. (2003) used the terms "general behavioral disturbance and manipulative behaviors" and Snow et al. (2007) measured and described "self-injurious behaviour". Therefore, the findings of this review are most applicable to those working with people with learning disabilities and are also relevant to the area of dementia care. Caution should be taken when considering their relevance to challenging behaviour due to other causes such as brain injuries. Additionally, all the studies that were conducted in the area of learning disabilities and two of those that studied dementia and older people recruited staff as their participant group. Consequently, the findings of this review can be said to apply to care staff but care should be taken when considering family carers as the majority of reviewed studies did not look at this group. Finally, there was a lack of geographical spread in the countries in which the reviewed studies were conducted. This may mean some care needs to be taken before applying the findings of this review to people in countries other than the United Kingdom.

Six of the reviewed studies used case vignettes, fictional examples of behaviour, instead of asking participants to access their thoughts on the behaviours of the people for whom they provide care. Dagnan (2012) compared carer responses to unnamed vignettes and

to behaviours by a person known to the carers. It was found that carers made more internal and global attributions and were less optimistic of change in relation to the named person compared to the unnamed vignette. Further, Wanless and Jahoda (2002) found that staff experienced a greater level of negative emotion in response to recalling an incident of aggression they had experienced compared to a descriptive vignette. Therefore the use of unnamed vignettes may mean that research studies do not represent an accurate picture of carers' "real life" attributions and emotional responses to challenging behaviour.

Some of the findings of papers in this review have particular implications for practice. The findings of Lambrechts et al. (2009) suggest a link between approaches taken to manage behaviours and attributions about those behaviours. Two of the three behavioural management response types described involved a form of restriction: "person-related restrictions" included using restraints to secure the person to their bed, and "environment-related restrictions" referred to practices such as locking windows or doors and preventing the person from entering a room. Associations were found between the use of these environmental restrictions and beliefs that the person's behaviours would not change over time (Lambrechts et al., 2009). This may be an area that warrants further research, particularly as while Lambrechts et al. conducted their study in Belgium, legislation in the United Kingdom would require a Deprivation of Liberty application to the Court of Protection for such measures under the Mental Capacity Act (Department of Health, 2005), with staff required to identify the least restrictive means of supporting the individual and avoid this type of restriction if possible. As this association is only a correlation, it cannot be asserted based on these results that either of these factors directly impact on the other. However, when considering the use of restrictive measures it is therefore advisable to be mindful that these may be associated with staff believing the behaviour to be due to a more permanent cause and less changeable than other forms of behaviour management.

Further practical implications can be drawn from the findings of Parker et al. (2012) who examined the impact of carer 'cognitive busyness' on attributions. They found that increased cognitive demands led to staff believing the causes of aggressive behaviours to be more internal to the individuals, and non-aggressive behaviours to be more under the control of the individuals (Parker et al., 2012). This relates to working environments and suggests it may be important to consider that when staff have a number of demands on their attention this may be associated with differences in how they understand clients' behaviours. This also carries relevance for other professionals who work with staff teams. Professionals should be aware of these wider, systemic factors and how they can impact on the attributions staff make about challenging behaviours as these attributions may influence how staff support the individual.

Some research has examined whether interventions to effect changes in staff responses to individuals with challenging behaviour, for example through the use of training in Positive Behaviour Support, result in changes in causal attributions (McGill, Bradshaw & Hughes, 2007). Williams, Dagnan, Rodgers and McDowell conducted a systematic review of the effects of carer training in behaviours in people with learning disabilities to determine if this resulted in changes in carers' attributions. They concluded that although changing attributions was usually not identified as an aim of training changes did occur, for example with staff making fewer attributions of control about clients following training (Williams et al., 2012). The findings of the current review suggest that believing the individual to have more control over their behaviours is associated with positive or social interventions (such as distraction) compared to environmental/ restrictive interventions (such as locking doors or tying the person to their bed), therefore beliefs about behaviours and training in behavioural management techniques appear to be linked. This is an area that warrants further research, for example by trialling the inclusion of information regarding the possible role of

attributions in responses to challenging behaviours in training packages to investigate any

benefits of staff being aware of these factors.

In conclusion, this review found sixteen studies that had examined one or more

factors in relation to the attributions carers make about challenging behaviour. The wide

range of factors studied meant there are few clear findings from the review itself. However a

number of clinical implications and areas for future research have been identified.

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┌─────────────────┐  ┌─────────────────┐  ┌─────────────────┐
│ 1160 records    │  │ 646 records     │  │ 298 records     │
│ identified from │  │ identified from │  │ identified from │
│ PsycINFO        │  │ Web of Science  │  │ CINAHL          │
└─────────────────┘  └─────────────────┘  └─────────────────┘
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Total of 2104 records identified through database searching

1771 records following removal of duplicates from search results → 1433 records excluded (not relevant to topic area)

338 articles screened for eligibility → 320 articles excluded (did not fit inclusion criteria)

16 papers included in systematic review

Figure 1. **Flowchart summarising the study selection process.**

Table 1

Overview of reviewed studies

Authors	Participants	Design	Variables	Measures	Analysis	Results
Cook et al. (1995)	93 family carers for people with dementia 30 male; 63 female Age not reported Duration of caregiving: 5 – 180 months	Within group correlational analysis	Duration of caregiving Attributions	Older Person's Attributional Style Questionnaire Caregiver's Attribution Scale for Problem Behaviours	Pearson's correlation	Significant correlation between longer duration of caregiving and carers making more stable, global attributions ($r = 0.25$)
Dagnan et al. (2004)	43 paid carers of older people with challenging behaviour Gender and age not reported specifically for this subgroup of the large study Experience not reported	Within group correlation	Attributions of control Coping style	Controllability Beliefs Scale The Shortened "Ways of Coping" Questionnaire	Pearson's correlation	Beliefs of controllability associated with emotion focussed coping style ($r = 0.46$), not problem solving focussed Situations where carers did not think clients had control over their actions were not associated with coping style
Dilworth et al. (2011)	139 staff who work with people with learning disabilities 31 male; 108 female Age 16 – 66 Experience: 0 – 31 years, median 6 years	Cross-sectional survey (between groups)	Staff characteristics (age, number of years worked, number of hours worked) Frequency/ severity of the challenging behaviour Service organizational functioning Perceived control client has over	Demographic information Disability Assessment Schedule Adaptive Behaviour Scale Service System Assessment Controllability Beliefs Scale	Spearman's rho correlations	No significant correlations between attributions of control and staff age, numbers of years worked with people with learning disabilities, number of years worked in current location or number of hours worked. No significant correlation between attributions of control and ability of the individual

			behaviour (attributions)			Significant negative correlation between attributions of control and the level of functioning of the organisation ($\rho = 0.38$)
					T tests	No significant difference in attributions of control with respect to staff gender Staff ratings of control lower if an independent rater indicated that 1) staff displayed positive attitudes towards the client; 2) the physical and social environment was appropriate; and 3) the overall approach to delivering care seemed well-structured
					ANOVAs	No significant effect of staff shift pattern on attributions of control Significant main effect of severity of the management problem behaviour posed and frequency for each behaviour on attributions of control

					Post-hoc Fishers Least Significant Difference Tests	Staff rated behaviour as more under person's control if physically aggressive behaviour presented a more severe management problem and was more frequent. Staff made more attributions of control over self-injurious behaviour where it posed a more severe management problem and was more marked in frequency.
Hill & Dagnan (2002)	33 staff who work with people with learning disabilities 8 male; 25 female Age not reported Experience: mean 10.8 years, SD 10.3	Within group questionnaire correlational analysis Vignettes	Staff coping style ('wishful thinking' or 'practical coping') Emotional responses Attributions (internality, stability, globality, controllability)	Attributional Style Questionnaire Shortened Ways of Coping – Revised Questionnaire Emotional responses measure	Pearson's correlations	No significant correlations between wishful thinking or practical coping styles and attributions Significant negative correlation between attributions of internality and feeling sympathy ($r = 0.51$), and positive correlation between stability and sympathy ($r = 0.62$)
Kleinberg & Scior (2014)	160 staff working with people with learning disabilities 67 male; 83 female Age 19 – 64, mean	2x2 between subjects design Vignettes	Staff gender Service user gender Outcome variable: staff emotional, attributional and	Emotional Reactions to Challenging Behaviour Scale Revised Causal	ANOVA	No effect of staff or service user gender on staff attributions of externality or control

	36.5 Experience: not stated but minimum 2 months to be included		behavioural response to physical aggression (using vignette)	Dimension Scale Authors own scale to measure behavioural intentions	Linear regression	Length of work experience and training received did not predict attributions
Lambrechts et al. (2009)	51 staff working with people with learning disabilities 3 male; 48 female Age 20 – 53, mean 34.27, SD 9.71 Experience: 0.5 – 33 years, mean 12.07, SD 9.06	Exploratory correlational design	Attributions Emotional Reactions to behaviour Responses to behaviour	Challenging Behaviour Attributions Scale Emotional Reactions to Challenging Behaviours Scale Reactions to Challenging Behaviour Scale (authors' own)	Pearson's correlations	Correlation between environment-related restrictions response to behaviour and attributions of stability ($r = 0.28$) Correlation between positive/ alternative interventions and attributions of controllability ($r = 0.50$)
Martin-Cook et al. (2003)	37 family carers for people with dementia (primary caregivers) Gender and age not reported Experience: not reported	Treatment group and control (all baseline values used for this review)	Caregiver resentment Caregiver depression Controlling or manipulative behaviours	Caregiver Resentment Scale Center for Epidemiological Studies Depression Scale Steinmetz Control Scale	Pearson's correlations	Association between belief that behaviours are under person's control and caregiver resentment ($r = 0.72$) and depression ($r = 0.59$)
Mills & Rose (2011)	77 staff working with people with learning disabilities 23 male; 54 female Age 18 – 62, mean 37, SD 11.89 Experience: 3 – 387 months, mean 101, SD 97.89	Exploratory correlational design	Staff burnout Perceived control client has over behaviour	Maslach Burnout Inventory Controllability Beliefs Scale	Spearman's Correlations	No significant correlation found between staff burnout and perceived control

Parker et al. (2012)	30 care staff from residential/nursing homes for people with dementia 4 male; 26 female Age: mean 34.9, SD 14.4 Experience: mean 7.1 years, SD 9.22	Cross-over experimental – conditions of 'cognitive busyness' and control Vignettes	Attributions Cognitive busyness vs control	Bespoke self-report causal attribution scale Controllability questionnaire	Pearson's correlation	No correlation between length of time working in dementia care and attributions
					Independent samples t-tests	More internal attributions made under conditions of cognitive busyness for aggressive behaviours; no difference for non-aggressive behaviour More controllability attributed to non-aggressive CB under cognitive busyness; no difference found for aggressive CB
Rose & Rose (2005)	107 staff working with people with learning disabilities 31 male; 76 female Age: mean 35.73, SD 11.05 Experience: mean 72.68 months, SD 81.04	Within groups questionnaire	Attributions Staff stress Staff burnout	Attribution Style Questionnaire General Health Questionnaire Maslach Burnout Inventory	Pearson's correlations	Stress not correlated with attributions of internality, controllability, globality, stability
					T tests	No significant differences between attributions made by staff working in high and low CB environments

Snow et al. (2007)	41 staff from inpatient services for people with learning disabilities Gender and age not reported Experience with LD: mean 117.15 months, SD 83.32 Experience with LD and self-injurious behaviour: mean 82.64 months, SD 82.64	Within group Vignettes	Attributions Staff burnout	Leeds Attributional Coding System Maslach Burnout Inventory	Spearman's Correlations	Correlation between increased time having worked with self-injurious behaviour and more attributions in total as well as more internal ($\rho = 0.40$) and unstable ($\rho = 0.35$) attributions. No correlation of attributions with age or length of time worked with LD Negative correlation between emotional exhaustion and frequency of stable attributions ($\rho = 0.30$)
Stanley & Standen (2000)	50 care staff who work in challenging behaviour day services 14 male; 36 female Age: mean 33.39, SD 12.02 Experience: mean 93.38 months, SD 69.87	Within group Vignettes	Carer attributions Type of behaviour Level of functioning of individual	Attribution Likert scales Behaviour/ functioning varied using vignettes	ANOVA	Significant effects of type of challenging behaviour and level of dependency on attributions of control and stability

					Post-hoc Tukey's Honestly Significant Difference test	Greater perceived control for aggressive behaviour than for self-injury and for independent functioning over dependent Greater perceived stability for self-injury over aggression or destructiveness, and dependent functioning over independent
Tarrier et al. (2002)	100 family carers (primary carers) for people with dementia 43 male; 57 female Age: mean 63.1, SD 13.6 Experience: mean 35.2 months, SD 28.7	Within group	Carer attributions Carer expressed emotion Carer strain Carer distress	Leeds Attributional Coding System Expressed Emotion – Camberwell Family Interview Gilleard Strain Scale General Health Questionnaire Clinical dementia rating	T tests	Carers with high EE attributed CB to causes that were more personal to and controllable by the individual.

| | | | | | Pearson's correlations | Positive correlations between carer criticism and hostility and attributions to causes personal to individual (both $r = 0.33$) Positive correlation between carer criticism and attributions of controllability ($r = 0.26$) Carers high in emotional over-involvement more likely to attribute behaviours as external to the individual ($r = 0.21$) and internal to themselves ($r = 0.24$) Negative correlations between attributions of stability, and increasing severity of dementia ($r = 0.20$) and reduced ability to carry out activities of daily living ($r = 0.24$) Positive association between attributions as internal to carer and dementia severity ($r = 0.22$), increased cognitive impairment ($r = 0.23$) and activities of daily living ($r = 0.29$) No correlation between attributions and individuals age or duration |

						of dementia No correlation between distress and attributions. Carer strain positively correlated with attributions of CB as more personal to ($r = 0.24$) and controllable by ($r = 0.24$) individual
					Friedman tests	Significant effects of cognitive and noncognitive effects of dementia and activities of daily living on attributions
					Post-hoc Wilcoxon tests	Carers made more attributions personal to and controllable by person about non-cognitive features than cognitive More controllable attributions made for activities of daily living than for cognitive features
Tynan & Allen (2002)	42 staff working with people with learning disabilities 62% and 57% of participants female in 2 conditions Age: 90% aged 21 – 45 years Experience: condition 1 4 months – 11 years, mean	Between participants Vignettes	Level of service user cognitive impairment (independent variable) Staff attributions	Causal attributions questionnaire Challenging Behaviour Attributions Scale	Mann-Whitney U	Service user in mild disability condition perceived to have significantly more control over their aggressive behaviour than the severely disabled person. No difference found for ratings of locus or stability

	4years 8 months; condition 2 8 months – 20 years, mean 6 years 10 months					
Weigel et al. (2006)	14 staff working with people with learning disabilities Gender and age not reported Experience not reported	Within group	Attributions Staff expressed emotion	Attributional questionnaire Expressed emotion - Five Minute Speech Sample rated by researchers	Wilcoxon sign test for related samples	Staff with low EE more likely to attribute CB as external to client and uncontrollable by client/ high EE more likely to attribute CB as internal, controllable
Zijlmans et al. (2012)	99 staff working with people with learning disabilities 35 male; 64 female Age: mean 33.7, SD 10.1 Experience: mean 10 years, SD 9.5	Within group	Type of challenging behaviour Staff attributions	Challenging Behaviour Attribution Scale	ANOVA	Staff attributed higher levels of controllability to clients whose behaviour was directed at their environment or their environment and themselves, compared to directed at themselves only. No significant effect of type of behaviour on stability.

Table 2

Quality assessment of reviewed studies

Item no. (max score)	1 (2)	2 (1)	3 (1)	4 (1)	5 (1)	6 (1)	7 (1)	8 (1)	9 (1)	10 (1)	11 (1)	12 (3)	13 (1)	14 (2)	15 (1)	16 (1)	17 (1)	18 (1)	19 (1)	20 (1)	21 (1)	22 (1)	Score
Cook et al. (1995)	2	1	1	1	1	1	1	1	1	0	1	3	1	2	1	0	1	1	1	1	1	0	23
Dagnan et al. (2004)	2	1	1	1	1	0	1	1	0	0	1	3	0	1	1	0	1	1	0	0	1	0	17
Dilworth et al. (2011)	2	1	1	1	1	1	1	1	0	0	1	3	1	2	1	0	1	1	1	1	1	0	22
Hill & Dagnan (2002)	2	1	1	1	1	1	1	1	0	0	1	3	1	2	1	0	1	1	0	1	1	0	21
Kleinberg & Scior (2014)	2	1	1	1	1	1	1	1	1	0	1	3	1	2	1	1	1	1	1	1	1	0	24
Lambrechts et al. (2009)	2	1	1	1	1	1	1	1	1	0	1	3	1	2	1	0	1	1	1	1	1	0	23
Martin-Cook et al. (2003)	2	1	1	1	1	1	1	1	0	0	1	3	1	0	1	1	1	1	1	1	1	1	22
Mills & Rose (2011)	2	1	1	1	1	1	1	1	0	0	1	3	1	2	1	0	1	1	1	1	1	0	22
Parker et al. (2012)	2	1	1	1	1	1	1	1	1	1	1	3	1	2	1	1	1	1	1	1	1	0	25
Rose & Rose (2005)	2	1	1	1	1	1	1	1	1	1	1	3	1	2	1	1	1	1	1	1	1	0	25
Snow et al. (2007)	2	1	1	1	1	1	1	1	0	0	1	3	1	1	1	0	1	1	1	1	1	0	21
Stanley & Standen (2000)	1	1	1	1	1	1	1	0	0	0	1	3	1	2	1	0	1	1	0	1	1	0	19
Tarrier et al. (2002)	2	1	1	1	1	1	1	1	1	0	1	3	1	2	1	1	1	1	1	1	1	0	24

Tynan & Allen (2002)	2	1	1	1	1	1	1	1	0	0	1	3	1	2	1	0	1	1	0	1	1	0	24
Weigel et al. (2006)	2	1	1	1	1	1	1	1	0	0	1	3	1	0	1	0	1	1	1	1	1	0	20
Zijlmans et al. (2012)	2	1	1	1	1	1	1	1	1	0	1	3	1	2	1	1	1	1	1	1	1	0	24

Appendix A

STROBE Checklist

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up
		Case-control study—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls
		Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed
		Case-control study—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is

		more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed
		Case-control study—If applicable, explain how matching of cases and controls was addressed
		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		*Case-control study—*Report numbers in each exposure category, or summary measures of exposure

		*Cross-sectional study—*Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion

Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix B

British Journal of Clinical Psychology Author Guidelines[1]

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjcp/. The Journal operates a policy of anonymous peer review. Before submitting, please read theterms and conditions of submission and the declaration of competing interests.
4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

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[1] Retrieved from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8260/homepage/ForAuthors.html

• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found athttp://authorservices.wiley.com/bauthor/suppmat.asp
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Section Two: Research Paper

An Exploration of the Emotional Experiences of Staff Working with Challenging

Behaviour in a Dementia Care Setting

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Abstract

People with dementia can behave in ways that present challenges for care staff. This has been shown to have an emotional impact on staff, which can affect how they respond to the people with whom they work.

Objectives

The aim of this research paper was to explore the emotional experiences of staff working in a residential care setting with people who have dementia and challenging behaviours.

Method

Nine paid care staff working with people with dementia and challenging behaviour took part in individual semi-structured interviews. Interpretative phenomenological analysis was used to analyse the data.

Results

Three broad themes were constructed: "They don't know what they're doing": Understanding causal attributions; "It's knowing them as people": Getting to know people with dementia; and "That's part of the job": Experiences of the role of care staff.

Conclusion

Directions for future research are discussed.

Keywords: dementia, staff, behaviour, emotions, attributions

Introduction

"Dementia" is a term that can be applied to people with a number of different disorders, with the most common being Alzheimer's disease (Stokes, 2000). Dementia has been commonly assumed to be caused by a neurobiological process involving a deterioration of the brain and loss of cognitive functioning (Stone, Johnstone, Mitrofanis, O'Rourke & Chang, 2015). This does not provide an adequate explanation of the behavioural effects however, and it is now widely recognised that many personal and social factors also contribute to the impact of dementia on a person's quality of life and functioning (Hughes, 2011; Moniz-Cook, Stokes & Agar, 2003).

People with a diagnosis of dementia can experience a number of difficulties, one of which is challenging behaviour, also referred to as behaviours that challenge (James, 2011). While challenging behaviours are often considered to be a direct result of degeneration of the brain (Porsteinsson & Antonsdottir, 2015), psychosocial factors also play a significant role in causing and maintaining them (Moniz-Cook et al., 2003). However, difficulties associated with dementia (including challenging behaviour) mean some people become unable to continue living at home and it can then be necessary for them to live and be supported in a residential care setting (Stokes, 2000). Indeed, in the United Kingdom, one third of people who have a diagnosis of dementia live in supported living, receiving support from paid carers (Alzheimer's Society, 2015).

Examples of challenging behaviours include agitation, verbal and physical aggression, self-injury and sexually inappropriate behaviour (Hughes, 2011). These behaviours are also referred to by other terms, such as the 'neuropsychiatric' symptoms of dementia (Porsteinsson & Antonsdottir, 2015) or 'behavioural disturbances' (Martin-Cook, Remakel-Davis, Svetlik, Hynan & Weiner, 2003). There is some difficulty in grouping all challenging behaviours together as they impact on the person and others to varying extents. For example, behaviours such as self-injury or aggression pose a clear risk to the individual.

Behaviours such as physical aggression could put other people at risk, which may include family members or other residents and staff in a residential care setting. Finally behaviours such as wandering may pose a challenge for those caring for the individual, but will not always present a danger to the person (Wigg, 2010).

The risk to others from challenging behaviours is not merely to physical safety. A literature review by Pulsford and Duxbury (2006) found that care staff who experience aggressive behaviour from people with dementia can experience a significant level of stress, negative emotion and burnout as a result. The authors suggested that the perceived threat of aggression results in increased stress levels and when this is the case over time it can lead to emotional exhaustion (Pulsford & Duxbury, 2006). In their interviews with female care staff working in nursing homes, Isaksson, Åström and Graneheim (2008) found that perceptions of experiencing violence varied. Violence was described by the care staff as: challenging, with accounts of the distressing nature of being under attack; excusable, with staff acknowledging that violence may occur because residents become frightened when they do not understand what is happening; and ordinary, with violence described as a part of the job (Isaksson et al., 2008). Isaksson et al.'s (2008) findings suggest that care staff experience a high level of emotion as a consequence of working with challenging behaviours. However, the focus was on "violence" (physical aggression) only, without mention of how other behaviours might impact on staff.

Indeed, limited exploration has been conducted of care staff's emotional experiences of working with challenging behaviour in published research to date. Lambrechts and Maes (2012) interviewed care staff working with people with learning disabilities about incidents where they had responded to challenging behaviour and their emotional responses. Using content analysis, they found that staff reported feeling negative experiences such as stress, anger, frustration, feelings of failure and pain for the clients, as well as positive experiences such as feeling calm, relieved, and confident. Some of the staff spoke of needing a break

after managing challenging behaviour and of finding themselves thinking about it afterwards (Lambrechts & Maes, 2012). However, while the findings of Lambrechts and Maes could be suggested to apply to the area of dementia care generally, there may be demands within an older adult dementia care setting that arouse different emotional experiences for staff.

While there is limited research focussing on the emotional experiences of staff, Berg, Hallberg and Norberg (1998) explored nurses' experiences of working in dementia care using a qualitative approach. They reported that nurses tried to understand people with dementia by making meaning from their behaviours; this could be achieved through empathy and knowledge of the person. They also described caring for people with dementia as having positives and negatives, with job satisfaction and a sense of interaction with those being cared for balanced against negative feelings such as frustration and powerlessness (Berg et al., 1998). Pulsford, Duxbury and Hadi (2011) surveyed dementia care staff to investigate their attitudes towards aggressive behaviour and found that the views expressed fit with a person-centred, psychosocial approach. The staff believed aggression by people with dementia to be caused by factors in the environment, situation or interpersonal interactions (Pulsford et al., 2011). Hayward, Robertson and Knight (2012) explored staff experiences of inappropriate sexual behaviour in dementia. They found that this type of behaviour could cause staff to feel shocked and embarrassed, noting that staff often minimised the emotional impact of this by attributing a lack of control to the individual (Hayward et al., 2012).

Expanding on the importance of staff emotions in dementia care, it has been suggested that the association between challenging behaviours and their impact on staff wellbeing is mediated by the negative emotional reactions of staff (Hastings, 2002). Moreover, care staff's emotional reactions to the people for whom they provide care can be influenced by staff's attributions about the cause of those behaviours. Attribution theory describes how individuals make sense of the causes of events or behaviours (Försterling, 2001). Dupuis, Wiersma and Looiselle (2012) found that in order for staff to form a response

to difficult behaviours they made interpretations about the behaviours. The first step in this process was viewing the behaviour in the context of pathology. If the person was considered to have dementia staff were less likely to take that individual's actions personally, as the individual was then considered not to be responsible for their behaviours (Dupuis et al., 2012). This suggests that if staff could attribute the cause of the behaviour to dementia rather than to the person, they were less likely to feel negatively towards that person.

Consequently, as can be seen there is very little research in the area of staff emotional experiences of working with challenging behaviour when caring for people with dementia. The area would benefit from a qualitative study exploring in depth the emotional experiences of staff in this setting. For the exploratory stages of research (Brown & Lloyd, 2001), or where there are gaps in knowledge (Elliott, Fischer & Rennie, 1999), qualitative investigation is recommended. The aim of the current study was to use a qualitative methodology, namely Interpretative Phenomenological Analysis (IPA), to explore dementia care staff emotional experiences further.

Specifically, this study explored the emotional experiences are of care staff who work with people who have dementia and who present with challenging behaviours in a residential care setting.

Method

Participants

Nine staff working in a paid carer role in three registered care homes in the North West of England took part in the study. All homes included residents with dementia and who presented with behaviours that challenge. Four described their job title as "carer", two as "team leader", two were nurses and one was a care home manager. To ensure participants had an appropriate level of experience in this setting, staff who had worked in a direct care capacity for at least six months full time (or equivalent) were eligible for inclusion. The

participants' length of experience in this setting ranged from 6 months to 27 years ($M = 9.5$

years). Two participants were male and the remaining seven were female. Interviews were

conducted in English, which was the first language of all but one participant.

Ethics

Ethical approval was provided by my university ethics committee (see Ethics

Proposal). Consideration was given to the possibility of participants experiencing distress as

a consequence of talking about their emotional experiences. If this were to happen, the

participant would have the opportunity to discuss this with me at the time of their interview

or would be directed to other appropriate sources of support. It was acknowledged that

participants may not have wished their manager to be aware of their participation in the

study; this was the reason for an alternative meeting place being offered. A final ethical issue

was that of the potential for participants to make disclosures which led me to believe there

was a risk of harm to the participant or others. It was made clear in the participant

information sheet and consent form (see Ethics Proposal Appendices C and D) that if this

were to occur then I would need to consider breaking participant confidentiality in order to

take appropriate action.

Procedure

Potential participants were identified by my supervisor who approached care home

managers to ask if they would allow their staff to take part. I then met with care home

managers and potential participants to provide information about the study using the

participant information sheet (see Ethics Proposal, Appendix C). Individual semi-structured

interviews were used to collect data. The interviews took place at the participants' places of

work although an alternative location was offered. Prior to each interview commencing

written informed consent was obtained with the consent form (see Ethics Proposal, Appendix

D). The interview schedule, which was constructed for this study, was used to guide each interview (see Ethics Proposal, Appendix B). Prompts and follow-up questions were used to elicit further information where I felt it appropriate. Interviews were recorded using a digital recorder and then transcribed verbatim by me. Full consent was gained to use verbatim quotes in the final write-up of the research and pseudonyms were given to all participants to protect their anonymity.

Data analysis

The transcripts were analysed using an interpretative phenomenological approach as described by Smith, Flowers and Larkin (2009). IPA can be used to explore participants' experiences, focussing on the perspective of participants and on how they take meaning from their experiences. It is recognised that the researcher's perspective will play a role in the analysis (Larkin, Watts & Clifton, 2006). IPA involves a "double hermeneutic" where the researcher endeavours to make sense of the participant, who is making sense of their experience. The researcher is only able to access the participant's experience through the participant's own understanding of it (Smith et al., 2009).

For each transcript, the first stage was an initial reading of the transcript for me to familiarise myself with the data. Next, initial annotations were made on the transcript, including any descriptive, linguistic and conceptual notes. These notes were then pulled together into emergent themes. These emergent themes, while still grounded in the participant's account, reflected some interpretation from me. For a sample of transcript with the initial annotations and emergent themes, see Appendix A. The next stage involved pulling the emergent themes together into a set of superordinate themes. This was an iterative process, facilitating the construction of themes that I felt best represented the participant's account. Appendix B contains an account of the superordinate themes for one participant and the emergent themes that led to these.

This process was repeated for each transcript. Consistent with the aims of IPA, an idiographic approach was taken, where I attempted to analyse each transcript in isolation, without influence of the previous transcript analyses. The themes from all participants were then analysed together, to look for patterns across the accounts and to identify the broad themes within the data set.

Ensuring the Quality of the Analysis

Quality in qualitative research is understood as effort to ensure the analysis is a credible interpretation of the data, while also acknowledging that it will not be the only possible credible interpretation (Smith et al., 2009).

During data collection and analysis I maintained an awareness of my potential influence and attempted to minimise this as much as possible. To this end, open-ended and non-leading questions were used in interviews in order to elicit the participant's own account rather than an account shaped by my assumptions. I was conscious that if I were to phrase a question clumsily the participant could give a response that was in line with the assumption within my question rather than representative of their own understanding or experience. One example of this was that when a participant had described an event I would ask an open question such as "How was that?" instead of a leading question such as "Was that difficult?". Further, I had assumed that all participants would have experienced some strong emotional reactions to their work with challenging behaviour. When a participant said something that was incongruous to this expectation, care was taken to fully explore the line of discourse.

During analysis I took care not to take any participant quotes out of context. Complete records were kept of the entire analytic process, meaning the interpretations can be traced from the broad themes, to the emergent themes from each participant, back to the raw data. The final broad themes have been demonstrated by the use of direct quotes from participants in order that the reader can judge the reliability of the interpretations.

Results and Discussion

Three broad themes were constructed: "They don't know what they're doing": Understanding causal attributions; "It's knowing them as people": Getting to know people with dementia; and "That's part of the job": Experiences of the role of care staff. See Appendix C for a list demonstrating how superordinate themes from each participant contributed to these broad themes.

"They don't know what they're doing": Understanding Causal Attributions

This theme captured participants' perceptions of dementia and challenging behaviour. Many participants described that in their experience people with dementia are different from how they were before. This change in people with dementia was described by participants as sad, as a result of an awareness of the contrast between the person now and how they used to be. There was also sadness for what the person had lost, shown in the following quote from Ainsley: "It's just sad… when you look at how much the condition changes them". This reflects research which has suggested that people with dementia experience a number of losses as a result of the condition and the diagnosis; as well as their cognitive functioning they can lose parts of their identity and connection to the social world (Cheston & Bender, 1999).

Participants understood this change to be due to the dementia, for example: "Their family… say they've never been like this… I think it's the illness, and I guess it really depends on which part of the brain it's affecting" (Rose). The fact that Rose understands the effects of dementia to be a direct result of parts of the brain being affected fits an explanation of the process of dementia being due to neurobiological changes.

This has implications for how staff interpret behaviours and the level of autonomy they believe residents have. This fits with the findings of Dupuis et al. (2012) who noted that where the cause of a behaviour could be attributed to dementia staff did not take the

behaviour personally, suggesting they did not hold the individual responsible. This also

resonates within attribution research, which has found that believing a person not to be in

control of their situation is associated with sympathy or pity, whereas believing them to be in

control is more likely to be associated with anger (Försterling, 2001). Attributing the cause

of challenging behaviours to dementia rather than to the person could allow staff to have

different emotional experiences from those that would be expected if they believed the

residents to have more control over their actions. This different experience of the residents'

behaviour is expressed by Frances: "If somebody came up to me that I knew that they knew

what they were doing… and hit me I wouldn't be happy about it, but… I know that [people

with dementia] don't know what they're doing."

Linked to the understanding of dementia as a neurobiological disease process, some

participants named changes in the brain due to dementia as the cause of challenging

behaviour. However, all also referred to environmental causes and triggers for challenging

behaviours. The perspective of participants who spoke about both neurobiological and

environmental causes of dementia is illustrated by Rose:

> I think [the challenging behaviour] is the illness [dementia], and I guess it really
>
> depends on which part of the brain it's affecting and the person's basic reaction as
>
> well to their environment.

This captures the understanding of challenging behaviour in dementia as being due to both a

disease process in the brain and environmental factors. This reflects other research such as

Hinton, Chambers and Valásquez's (2009) finding that family caregivers of people with

dementia made a variety of attributions about the causes of challenging behaviour, including

the effects of dementia on the brain, interpersonal issues and emotional distress.

When giving their understanding of how environmental factors could lead to

challenging behaviours, many participants described their own experiences of the

environment of the care home. They used their experiences to identify ways in which it might be difficult for the people living there, leading to behaviours that are challenging:

[They were] living at home with their loved ones… and all of a sudden they're in this big establishment with lots of people running around that's very noisy and very busy, and that I guess can trigger all kinds of behaviour. (Rose)

A particular trigger that was identified for challenging behaviour was personal care intervention. Participants empathised with how this might be experienced by the person and why this could lead to them becoming agitated. Participants spoke of people with dementia being unable to understand situations or staff's attempts to communicate with them and the emotions that might be associated with this for residents. This way of interpreting situations was linked to a sense of empathy for why these emotions would lead to challenging behaviours:

When we need to sort of change them or wash them and dress them in the morning a lot of them can be quite aggressive, and I think I would be if I had people coming into my room and doing things with me that I didn't know what they were doing. (Frances)

This difficulty with communication was understood by participants to be present in the opposite direction too, with people with dementia having trouble making themselves understood to staff and this having an impact on their emotions which could then affect their behaviour: "A lot of the residents as well aren't able to express verbally that they're unhappy… and because they can't express it they get frustrated and angry, and then I guess really the aggression comes out because of that" (Rose).

When it came to behaviours that challenge, most participants were clear that people with dementia had little or no control over their behaviours:

It's not them that's the problem it's the dementia… The aggression… the hitting out

at staff and that, it's because of their condition that's caused it, not because they are a

nasty person, a violent person. (Sam)

This understanding of there being a contrast between aggression that is due to

dementia and not under the person's control, and violence which would be considered an

intentional act by the person, is consistent with the findings of Isaksson et al. (2008). They

found that care staff drew a distinction between aggression that was not the fault of the

individual, and acts they described as "violence" which were under the individual's control.

The perception that people with dementia have no control over their behaviour was described

by a number of participants as a reason why they did not experience negative emotions

towards the residents when they were aggressive: "I know it's not that person that's smacking

me, knocking my glasses off and giving me a black eye. I know it's not them that's doing it

it's the condition… so it doesn't affect me". (Sam)

The idea that it is not the person but the dementia that causes challenging behaviour

was further supported by many participants' views about how they imagine the people they

work with would feel if they were aware of what they were doing. Empathising with how the

person would feel if they were aware of their actions had an emotional impact on some

participants: "I get upset, because I think if they knew that they've done that they would be

horrified" (Sam)

While this sense of how the person would feel if they were aware of their actions

could be upsetting, it was also experienced as a reason not to have a negative reaction to the

person: "you can't take anything personal because if they knew what they were doing they'd

be mortified… it's not them, it's their disease" (Pat). The implication of participants

believing challenging behaviours to be caused by dementia rather than the person is that they

do not think people with dementia are in control of their behaviours.

However, some participants' use of language suggested that they may not be certain of this lack of control. One participant explicitly attributed intent to harm to people with dementia: "just them sort of trying to hurt you" (Frances), although this statement was not representative of the perspective Frances expressed during the rest of her interview (see below). A number of participants used the word "abuse" when referring to aggression against staff, a word which carries associations with deliberate acts inflicted on another. Further, Frances referred to "forgiving" residents for injuries sustained through physical aggression, a word which carries with it the implication of some fault on the part of the other person.

> Moreover, Frances noted a specific trajectory in her perception:
>
> When I first started working here when I didn't understand dementia as much, there were a few negative feelings around why am I being punched… I think my understanding has gone from why am I being punched, it's their fault, to they've hurt me in a way but it's not their fault because they don't understand what they're doing.
>
> (Frances)

This quote highlights a shift in the causal attributions Frances makes about the behaviour of residents with whom she works. Interestingly Frances has identified her understanding of dementia as the reason for the change, which fits with the idea that as people with dementia have a physical deterioration of their brains, they cannot be held responsible for their actions. When Frances believed people with dementia to be able to control their actions, this led to "negative feelings", so it would fit that in order to feel more positive about her job role, a shift in attributions would be beneficial. The conflict described above where Frances at one point attributed intent to harm to the residents in a statement incongruous to the rest of her interview may suggest that her understanding of dementia and resulting attributions for the causes of challenging behaviour is still shifting. Cognitive dissonance theory states that when an individual holds multiple beliefs that are inconsistent, the resulting psychological

discomfort motivates them to alter their beliefs or behaviours to reduce this inconsistency (Festinger, 1957). Frances may have experienced a conflict between behaving in a caring way towards the residents and at the same time experiencing negative feelings towards them due to believing them to be responsible for their actions when they caused her harm. This may have caused her to shift her attributions as described above.

"It's knowing them as people": Getting to Know People with Dementia

This theme concerned participants' accounts of their experiences of getting to know the people with whom they work and the emotional experiences that are associated with these relationships.

Getting to know the residents better meant staff knew what they could talk to them about and how to engage with them, which could be a positive thing for the staff member, and was also felt to be beneficial for the person with dementia: "It's knowing them as people. And not just seeing them as a client, you know them individually, you know how to approach them, what they like, things that you can say to them" (Sam).

The above quote also mentioned seeing the whole person rather than seeing them as a "client". This implies that Sam considers it important to see past the dementia and the challenging behaviours to connect with the individual on a personal level. This idea of seeing the whole person was given by Rose as a reason that challenging behaviours do not affect how she feels about people with dementia:

> I think the reason that [the physical aggression] doesn't [affect how I feel about the person] is that you see the residents here and maybe what about 60-70% of the time there are no issues... You don't judge them on the small part of where there is an issue... we look at the person as a whole (Rose)

Keeping in mind the whole person is consistent with the idea of a person-centred approach to dementia care (Moniz-Cook et al., 2003). As person-centred approaches to care

have been included in the NICE-SCIE guidelines (NICE-SCIE, 2007) on dementia care, this

may be a result of staff receiving training in a person-centred approach. In person-centred

care the focus is on understanding the person, including their personality, relationships and

life experiences, all of which will influence how they respond to their situation and what

emotions they experience (Woods, 2001).

Trying to understand the residents was something that participants experienced as

being difficult at times, particularly in the later stages of dementia:

When they get to a certain stage, they can't tell you what the matter is… so you've

got to sort of try and think for them, and that can be problematic because who's to say

any of those things are right? (Frances)

This quote illustrates Frances' use of a person-centred approach to working with the

residents, of trying to understand their perspective even when they are unable to

communicate this for themselves. Connecting with the perspective of a person with dementia

who is unable to communicate verbally is challenging and will require staff to draw more

heavily on their own emotional experiences than they would have to with a person who was

able to articulate their feelings (Kitwood, 1997).

Other participants also spoke of the emotional impact of trying to understand the

perspective of a resident with whom they are working and finding it difficult: "I still can't

really figure out what's going through his head. And you really want to help him… but you

just can't. You feel helpless." (Brendan).

Several participants gave a perspective on challenging behaviour that might seem

surprising. They stated that they would prefer for people to act aggressively because this

meant the person's dementia had not deteriorated to the point where they were no longer able

to do so: "Just to see that deterioration from… the autonomy that he had earlier, to just being

completely dependent upon us… was actually really, really difficult to see… that tends to be

the time when the challenging behaviour starts diminishing" (Rose). This quote is interesting

because referring to the person as having had "autonomy" when he was challenging suggests an understanding of this gentleman as having had some control over his behaviour. However, this is at odds with the dominant narrative – as outlined in theme 1 – of people with dementia not being able to control their behaviour and therefore not being responsible for harm they cause to staff.

The participants described that in their experience residents would need to settle into the care home and become familiar with staff as well as staff needing to get to know them: "We've got to get to know them [residents] and they've got to get know us" (Karen). The concept of the people with dementia getting to know staff, and forming reciprocal relationships with them, also contrasts with the previous theme. When it came to understanding challenging behaviours, participants attributed little or no control to the people they work with and believed that they are unable to control their aggressive behaviour, meaning staff could avoid feeling negatively towards residents. However, the idea of people with dementia getting to know staff and forming relationships with them seems to attribute a greater level of cognitive functioning to residents. This could also serve a function for staff however, as in a job that can be difficult it may be helpful to experience the people they work with as reciprocating their positive regard. This is reflected in the link between care staff experiencing a lack of reciprocity in their relationships with residents and staff burnout (Duffy, Oyebode & Allen, 2009).

Several participants commented on the distress they felt when a resident died, noting how it was "very hard" (Drew). As the participants all described their experiences of feeling close to the people they worked with, it seems understandable that it would impact on them when someone died. At the end of the life of a person with dementia care staff often have a role to play in supporting them and their relatives, which one participant saw as a positive part of her job: "I like end-of-life care… I think it's a privilege. To be with them… I think I make them feel comfortable… And then I just hope that when it's my turn somebody is there

for me" (Karen). Working with people at the end of their lives has led Karen to reflect on her own mortality and to wonder what it will be like for her when she is at the end of her own life. While describing her experience that the death of a resident is sad, Karen gave her perspective on how to cope with it: "It's sad, but… I think how happy they were, and they were lucky to be here because we look after them… it's good here, I feel as though… you've just got to remember nice things about them."

This quote carries a sense of Karen's pride in her work. The final phrase in the quote with the statement "you've just got to" suggests a need to take this perspective, which may be in order to protect herself from the weight of negative emotion that could be associated with residents dying. Correspondingly, Albers, Van den Block and Vander Stichele (2014) surveyed nursing staff who had cared for people with dementia at the end of life and found that around a third experienced a high level of emotional burden. Albers et al. (2014) point out that while staff experiencing an emotional burden when residents are at the end of life could suggest staff feeling strained and at risk of burnout, it can be interpreted as being positive as it suggests that staff feel involved in caring for residents and have connected with them on an emotional level.

"That's part of the job": Experiences of the Role of Care Staff

This theme explores parts of participants' accounts that pertained to their feelings about their jobs and the things that impact upon them as care staff. The various demands of the job could lead to care staff feeling stressed, and some participants described the need to be simultaneously aware of many different things:

When you've got like let's say 10 people shouting and you have to watch them, and people are trying to stand up, but they're not meant to because they've just had let's say a hip replacement, and you try to settle them down and then there's the other

person over there shouting and then you think wow, I'm getting a bit stressed here

(Brendan)

This quote paints a picture of an environment where staff must be constantly vigilant and alert to situations to which they may need to respond. This constant vigilance is not dissimilar to the hypervigilance experienced by people who have anxiety difficulties (Richards, Benson, Donnelly & Hadwin, 2014). Maintaining this level of high alert over a long shift would inevitably impact on care staff. As well as the stress of many demands over a long period at work, care staff could also experience acute high stress while managing instances of challenging behaviour: "Your autonomic responses start kicking in, your heart starts racing, your palms start getting all sweaty" (Rose). This quote continues the idea that what staff experience is equivalent to an anxiety response, as Rose has described classic anxiety symptoms. This is of note as increased levels of staff anxiety have been shown to predict care staff in nursing homes perceiving challenging behaviours as being more difficult to manage (Moniz-Cook, Woods & Gardiner, 2000).

Following a difficult incident, several participants spoke of giving themselves time out to bring their level of stress down: "I nip outside for a quick smoke… other people will go and get a cup of tea or just get some fresh air…. to relax themselves back down again before they get back out there" (Rose). There is a clear sense that staff experience high stress as part of their job. When Rose was asked to elaborate on what felt difficult about incidents after which she would need a break, she responded with descriptions of what she meant by incidents being both upsetting and frustrating:

It's quite upsetting… your head's telling you you're doing it for the right reason, but it's not nice to see somebody so distressed… It's frustrating because… you know that what you're trying to do is for them, but they don't see that… it can be quite frustrating from that respect, of just trying to do the best for somebody but them not letting you. (Rose)

The use of self-care measures such as taking a break was a positive experience for staff, enabling them to continue with their shift and deal with the next situation requiring their attention. Operating at a high level of stress for a long shift could impact on how staff responded to situations:

You've been here so many hours, you're getting stressed… your mind is not working right anymore… sometimes you have to step back… give yourself five minutes… because you're only a human being (Brendan)

Moments like this could be when the staff increased their support of each other: "At that time of the day when you're tired and you're worn out… you start pulling together more as a team" (Rose). The participants' experiences of the importance of help from colleagues is consistent with the findings of Lambrechts and Maes (2012), whose participants identified help from colleagues as being important. Working with such a high level of stress could also impact on how participants felt when they got home: "When you get home and… you've been stressed all day … you feel drained." (Brendan)

Related to working as part of a team, there was a sense of participants feeling a responsibility to protect their colleagues: "If you're working with somebody and they get whacked you can sometimes feel a little bit guilty… maybe you should have done something to stop [it]" (Rose). It seems that experiencing a sense of responsibility to look out for colleagues can lead to feelings of guilt if colleagues get injured. In a survey of dementia care staff, Scott, Ryan, James and Mitchell (2011) found that following an incident staff valued reassurance from colleagues that they were not at fault.

This idea of staff feeling at fault links to the attributions staff make about behaviours because by taking the blame they are removing it from the people with dementia. This sense of staff being responsible also extended to taking responsibility for themselves getting hurt during incidents of challenging behaviour: "Somebody who is going to head-butt you, you don't go and stand in front of them because that would make no sense" (Rose).

Again, the above quote is about the staff member avoiding injury, suggesting that they do not believe the person with dementia to be responsible for their own behaviour. As discussed, this may serve a function of enabling the staff member to continue to care for the residents without feeling negatively towards them. A few participants spoke of feeling uncertainty in their own competence following situations where they had to manage challenging behaviour which they felt had not gone well: "Things like that happen and…. I just kind of feel a bit rubbish at my job" (Frances).

This quote also carries a sense of Frances feeling responsible for incidents of challenging behaviour, continuing the sense of participants understanding people with dementia not to be in control of their own behaviours. Feeling that they had not been able to manage situations as they would have liked to could lead to feelings of helplessness for participants: "When you… try to help them and you physically can't… you do feel helpless and you do feel sad" (Brendan)

Feelings of helplessness could also be part of the experience of trying to manage challenging behaviour with residents who could overpower care staff: "It can be quite frightening at times, we've got a few residents who are particularly strong, and you know that if the situation escalates with them… there is a very good potential of you getting hurt" (Rose). As well as a feeling of helplessness, this quote carries a sense of Rose feeling intimidated by residents at times. Something that was understood by some participants as being crucial to knowing how to manage situations was experience: "If there's someone who's maybe been in the job for just a month or two, that person probably wouldn't know what to do in that kind of situation" (Brendan).

A number of participants described their experiences of reflecting on situations where they have had to manage challenging behaviours, and considering whether they could have done things differently:

I usually think when I'm at home I'm at home, I try not to think about work. But

sometimes it just doesn't work like that… you think about it and you're thinking well,

what can I change maybe tomorrow to make it better. (Brendan)

Brendan describes the intention of protecting his time off and trying not to think about work,

but at times experiencing intrusive thoughts about situations and how he could have managed

them differently. However, this was not true of all participants as some felt that it was not

helpful to think back over situations and appeared to be able to maintain this boundary: "I

think it's just over with, there's nothing I can do about it… there's no point going over it"

(Jean). This contrast in experiences, between those who found it helpful to reflect on their

day and those that did not, was interesting, particularly given that an association has been

found between reduced job strain in dementia care nursing staff and opportunities for staff to

reflect on difficult situations at work (Edvarsson, Sandman, Nay & Karlsson, 2009).

There was an acknowledgement by many participants that working in a care home is a

job that can be emotional. Some participants spoke of the need to leave this emotion at work:

"We can't really take it in so much because otherwise you would be crying nearly every day.

And you have to get that… boundary around you" (Brendan).

Although many of the emotions of the job that were described sounded difficult for

staff to manage, there were positive aspects to the emotional experiences of working in a

dementia care setting: "These people are really nice when you start talking to them, and I just

get a lot of satisfaction out of feeling like I'm doing a really good job with them and sort of

making them happy" (Frances). Berg et al. (1998) also found that dementia care staff

identified both positive and negative experiences in their work.

Some participants stated that the good things about their job outweighed the bad: "I

think the good feelings about the job, the… satisfaction I get from it and the helping people

and… making people happy completely outweighs any of the bad stuff" (Frances).

It could be suggested that working in a job that can be emotional in the ways that have been described would mean that if someone did not find the positives in their work and experience an overall positive feeling towards their job they would experience burnout and be unable to continue in this role. Therefore the participants have likely all been able to find things to feel positive about in their work.

Conclusion

As outlined in the results and discussion section, the participants in this study described a range of emotional experiences associated with working with people who have dementia and behaviours that challenge. Some experiences related to participants' understandings of dementia and challenging behaviour, others were associated with getting to know the residents and the remainder were linked to experiences of the job, including high levels of stress and the need for breaks.

The most important finding from this study was the different attributions participants made about participants' control over their actions depending on the context. Understanding residents to have no control over their behaviours when they were aggressive towards staff meant staff did not have a negative emotional reaction to the person. This was linked to understanding dementia to be a disease process in the brain which caused the behaviours. However, people with dementia were also described in ways which attributed greater cognitive functioning to them, for example in participants' accounts of residents getting to know the staff. This was a positive experience for participants and therefore there were benefits to this type of attribution.

Significant research exists examining attribution theory in relation to the care of people with challenging behaviour, including people with dementia. Researchers have attempted to answer questions such as how carer attributions affect their expectations of people with dementia (Fopma-Loy & Austin, 1997), whether attributions are associated with

carer resentment (Martin-Cook et al., 2003), and whether carer coping styles are related to

differences in the attributions they make about behaviours (Dagnan, Grant & McDonnell,

2004). However, the findings of the present study relate to a different dimension of

attribution theory: the functions of different causal attributions of challenging behaviour for

care staff.

The findings of the current study carry implications for care staff and external

professionals. The merits of the move towards a psychosocial, person-centred understanding

of dementia have been clearly outlined (Cheston & Bender, 1999; Moniz-Cook et al., 2003;

Woods, 2001). This approach is embodied in models such as the Newcastle support model.

This model assumes that an individual's behaviours are driven by their needs and examines

them in this context, also using information from the person's background and their current

experiences (James & Stephenson, 2007).

The implications of the results of the current study should not be taken as a criticism

of such models, however it may be important to be aware of the role understanding dementia

to be a neurobiological process plays in allowing care staff to attribute challenging

behaviours to dementia rather than to the person. This means they are able to avoid having a

negative emotional reaction to that person (Dupuis et al., 2012). Professionals who work

with care staff using a person-centred approach should be sensitive to the fact that staff may

find it beneficial to be able to understand challenging behaviours from a neurobiological

perspective. However, acknowledging that these attributions may be helpful to care staff

does not detract from the need to move towards a more psychosocial understanding of

dementia (e.g. Moniz-Cook et al., 2003). The hope would be that using a person-centred

approach such as the Newcastle model would enable staff to continue to act and feel

compassionately towards residents while understanding challenging behaviours as an

understandable reaction for that person in their situation.

One way in which professionals can support care staff is by providing training on dementia. Staff who have greater knowledge about dementia and who feel more confident in providing care for people with dementia hold more positive attitudes towards residents with dementia (Leung et al., 2013; Travers, Beattie, Martin-Khan & Fielding, 2013). This fits with the results of the current study in theme one with Frances' account of her responses to residents' aggression changing over time as her knowledge about dementia increased.

Participants in the current study described experiencing high levels of stress and anxiety in their work and expressed the importance of taking breaks to manage their stress levels. However, there is a question of whether taking a break is always an option and there could be negative effects for staff of coping with repeated incidents without time out to reduce their stress levels. This carries implications for care home managers who may wish to examine what procedures they have in place to ensure their staff are able to take breaks when necessary.

A key limitation of the current study was that all participants were recruited from three care homes. Consequently, it is possible that shared narratives within the staff teams in these care homes resulted in less varied data than recruiting from more care homes would have provided. However, it was felt by the researcher that any impact of this on the data collected was minimal, as subjective differences were noted between accounts of participants recruited from the same care home (see Critical Appraisal for further discussion). Another possible limitation was that all participants were identified through contact with their managers; thus care home managers had the opportunity to select the staff who were asked to take part. This may not have had any impact on the results but it could be suggested that managers would have identified staff whose views they felt would reflect well upon the ethos of their care home.

Directions for future research can be proposed. The role of attributions in dementia care staff emotional experiences could be the focus of future research, perhaps by examining

staff attributions for different contexts in greater detail to understand the degree of any contrast. The current study did not compare participants' accounts with an independent measure of the severity of residents' impairment, something that future researchers could consider. Additionally, the current study found that care staff can experience a high level of stress throughout their shifts. It would be of interest to explore this further, for example by trialling the use of evidence-based relaxation techniques for staff and examining whether this impacts on their experiences. McConachie, McKenzie, Morris & Walley (2014) trialled an acceptance and mindfulness-based stress management workshop with support staff in a learning disability setting and found a significant reduction in staff stress.

The emotional experiences of care staff, how they understand dementia and the causal attributions they make about challenging behaviours are interlinked. It is important to consider the experiences of staff and the role of attributions when examining the needs of people who have dementia as well as those who care for them.

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Appendix A

Sample of Annotated Transcript for Rose

Initial Annotations	Text	Emergent Themes
Dementia leads to CB (challenging behaviour)

Sometimes CB comes from part of personality/ Sometimes complete change

Difficult for families to see

CB due to dementia process in brain CB partly environment

Person's good reasons for CB – empathy

Person can't express their wants – frustration – CB

Personal care as a trigger for CB

Want to respect person's wishes but certain things have to do

Try to reassure – they don't understand – of course they get upset/ frightened - CB | Interviewer (I): What do you think leads to people with dementia presenting with challenging behaviours ?
Respondent (R): Erm, ultimately I think it's the dementia. You know, erm you can speak to the families of our residents and erm through them they can gauge that sometimes there are behaviours that have always been there, such as there's some residents now that are quite vocal and quite erm angry in their tone of voice, and you speak to the family and they say "oh yeah, you know they've always kind of been a bit like that, they've always been a bit sharp" and that's one thing, and then you see other residents who've come in and their character has changed completely. Erm, their family are quite distressed and they say they've never been like this, you know they've never seen them in this way, erm they might be showing signs, well they might be swearing a lot or physically aggressive and previously they've been quite a mild and gentle person, so effectively I think it is the illness, and I guess it really depends on which part of the brain it's affecting, um and the person's basic reaction as well to their environment, because that's another side of it as well, you know the challenging behaviour can come from you know, before, living at home with their loved ones and you know quite a nice close-knit family area, and all of a sudden they're in this big establishment with lots of people running around that's very noisy and very busy, and that I guess can trigger all kinds of behaviour. Erm a lot of the residents as well aren't able to express verbally that they're unhappy in any way, or that you know they don't want assistance with such and such, they don't like the food they're eating and because they can't express it they get frustrated and angry, and then I guess really the aggression comes out because of that.
I: Mm, so quite a few different factors there… are there any triggers that you think there are for particular incidents?
R: Erm yeah, I mean if we're talking specifically about residents, erm I mean there's a few residents' aggression that's triggered just by staff carrying out care needs, erm unfortunately as the illness of dementia progresses a lot of the residents become incontinent and if we don't help them to maintain their hygiene and to wash and to change, then that puts their skin at risk and ultimately their health at risk, so you know it's not an area that we can just say oh you know you don't want that dealt with we'll just leave that then, unfortunately we have to sometimes roll up the sleeves and just get on in there and do it. And I think that can sometimes be a trigger for this aggressive behaviour, because as much as you try and reassure the person that you're dealing with erm what it is that you're doing, ultimately we've always been taught throughout our lives that nobody should be touching us in an area such as basically where we're dealing with, and I think that can be quite a frightening thing for a lot of the residents who're not actually understanding what we're trying to do. | Understanding of CB cause

Empathy for families

Understanding of dementia and CB causes

Seeing the person with CB

CB triggers

Understanding the person

CB triggers

Role of staff caring for person

Understanding the person |

Appendix B

How Emergent Themes Led to Superordinate Themes for Drew

Perspective on dementia and challenging behaviour

Understanding of dementia

Understanding of challenging behaviour

Triggers for challenging behaviour

Feelings about people with dementia

Connecting with people who have dementia

Understanding the person

The person can't help their behaviour

Sad when someone dies

Getting close to residents

Doing the job and letting it go

Attitude to the job

Leave emotions at work

Looking after self

Enjoying job

Experience increases confidence

Support from matron

Appendix C

How Superordinate Themes from Participants Contributed to Broad Themes

"They don't know what they're doing": Understanding causal attributions

Knowledge and understanding of dementia and challenging behaviour (Frances, Brendan, Sam, Jean)

Understanding and perception of dementia and challenging behaviour (Pat, Karen)

Knowledge and attitude to dementia and challenging behaviour (Rose)

Perspective on dementia and challenging behaviour (Ainsley, Drew)

"It's knowing them as people": Getting to know people with dementia

Knowing and understanding the person with dementia and challenging behaviour (Frances, Brendan)

Connecting with the people with dementia and challenging behaviour (Sam, Jean, Ainsley, Karen, Drew)

Understanding and caring for the person with dementia (Pat)

Seeing the person with challenging behaviour (Rose)

"That's part of the job": Experiences of the role of care staff

Highs and lows of the job (Frances)

The vulnerable carer (Frances)

Coping with the impact of the job on self and colleagues (Brendan)

The job and its impact (Sam)

It's just part of the job (Pat, Jean)

Getting on with the job: team support (Rose)

The perspective of carer (Ainsley)

Being part of the care team (Karen)

Doing the job and letting it go (Drew)

Appendix D

Aging & Mental Health Author Guidelines[1]

1. General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.

- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); tables with captions (on individual pages); figure captions (as a list). Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph:

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  This work was supported by the <Funding Agency> under Grant <number xx>.

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  This work was supported by the <Funding Agency #1> under Grant <number xx>; <Funding Agency #2> under Grant <number xx>; and <Funding Agency #3> under Grant <number xx>.

- Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

- Each manuscript should have 3 to 5 keywords.

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- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.

- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF and the online article.

- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.

- Biographical notes on contributors are not required for this journal.

- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.

- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.

- Authors must adhere to SI units. Units are not italicised.

- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM. Authors must not embed equations or image files within their manuscript.

2. Style guidelines

- Description of the Journal's article style. (See below)

- Description of the Journal's reference style. (Links to American Psychological Society (APA) guidelines)

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Section Three: Critical Appraisal

Critical Appraisal

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Overview of Results

In the current study (see Section 2) nine people who work as paid direct care staff in the area of residential dementia care were interviewed about their emotional experiences of working with challenging behaviours in this setting.   Interpretative phenomenological analysis was used to analyse the data and three broad themes were identified and described. The first theme, "They don't know what they're doing": Understanding causal attributions, described how staff made sense of the behaviours of the people they work with by understanding them to have little or no control over their actions. In this way they were able to believe that the residents in the care home did not intend them any harm by their aggressive behaviour. The theme "It's knowing them as people": Getting to know people with dementia described participants' experiences of becoming familiar with the people they care for, and of feeling that they developed an understanding of them. In this theme participants tended to attribute greater cognitive function to residents by believing that the residents grew to know them in turn. These relationships with residents were described as a positive experience. The final theme "That's part of the job": Experiences of the role of care staff, was an account of the participants' experiences of their jobs, the various demands and how these experiences impacted on them emotionally.

Within these results, the link to attributions is interesting as this relates to the topic of the literature review (see Section 1). This review sought to identify factors related to the attributions that carers (including staff) make about challenging behaviour. Of particular interest to the research study are the findings that the severity of an individual's cognitive impairment and the type of challenging behaviour can impact on the attributions that carers make about behaviours. In the area of dementia care, as dementia is a progressive condition this first finding may make it more likely that care staff make different attributions about the same person's behaviours, as in addition to other individual differences staff might have

different perceptions of the severity of that person's dementia. Care staff may also make

different attributions about different behaviours for the same person.

A key feature of the literature on the topic of behaviours that challenge is the contrast

between the perspective that challenging behaviours are a symptom of an underlying disease

(Stone, Johnstone, Mitrofanis, O'Rourke & Chang, 2015) and the description of behaviours

as being influenced by many factors, with challenging behaviours ultimately being a means

of communicating unmet needs (Cohen-Mansfield, 2000). The findings from the current

papers can be considered within the context of this divide.

A finding from the literature review (see Section 1) was that the type of intervention

used to manage challenging behaviour was associated with differences in the attributions

carers made about the behaviours. The way in which the underlying cause of behaviour is

understood links to the type of intervention that is considered most appropriate. Attributing

the cause of challenging behaviour to an underlying disease process naturally lends itself to

the use of medications to manage the behaviours, while considering behaviours to be

communicating unmet need is more likely to result in psychosocial interventions (Røsvik,

Brooker, Mjorud & Kirkevold, 2013). As the findings from the literature review were

correlational the cause of the difference in attributions associated with the type of

intervention is not known, however carers' beliefs regarding the underlying cause of

challenging behaviours may be a factor.

This divide in perspectives on the cause of challenging behaviours also links directly

to the results of the research study (see Section 2). Some participants spoke of dementia as a

disease process within the brain that directly leads to challenging behaviour. However all

participants spoke of environmental causes for behaviours, an explanation which sits on the

other side of the paradigmatic divide and takes account of other reasons for the behaviours. It

appears that it is possible to sit somewhere in the middle of these divided perspectives,

holding the belief that challenging behaviour is at least partly due to a disease process while also understanding it to occur in response to environmental factors and to be a way for the individual to communicate their distress or unmet needs.

The Research Process

For this research study I chose to use individual semi-structured interviews to collect my data. The advantages of this approach are that it facilitates a rapport between researcher and participant and also allows for greater flexibility of content and tends to lead to richer data (Smith & Osborn, 2003). Another option would have been focus groups, which are also widely used in qualitative research and can allow for more participants' data to be collected at one time, necessitating fewer arranged meetings for data collection (Smith, Flowers & Larkin, 2009). However, I do not think this would have been a better choice for the current study. One reason for this is that I am not experienced in running focus groups, and feel that the quality of data collected could have been limited by my being a novice at the running of focus groups. Further, the research question of my study related to emotional experiences, and I believe that collecting my data through individual interviews, allowing each participant's unique voice to be heard before collating the data, was the most robust way of exploring this topic (Smith et al., 2009). Focus groups are most appropriate for areas of debate and may reduce the quality of data in emotive or sensitive topic areas (Cleary, Horsfall & Hayter, 2014).

While participants were offered an alternative interview location, all chose to meet with me at their places of work. This was primarily because the interviews took place during their work time. In some ways I consider this to have been a positive aspect of the study, as participants were more willing to take part, and being in their place of work may have made it easier for them to connect with the emotional experiences associated with their job.

However, this did mean that many of the interviews took place in whichever room was vacant at the time, usually either an empty bedroom or the staff room. While this did not present any significant difficulties, it did mean that some of the interviews were temporarily interrupted by other members of staff coming into the room. The consequence of this was an interruption to the flow of the interview, with the participant possibly having been interrupted mid-sentence. I tried to minimise the impact of this by, once the person had left the room again, summarising for my participant what we had been talking about and what they had just said, to provide a prompt and attempt to get the interview back on track. However, I anticipate that this will have had some effect and some points made by participants may not be as fully developed in the data as they might have been without any interruptions. On balance I would not change having held the interviews at participants' places of work; however, I could have made it clearer that I would need a room where the interview would not be interrupted.

Strengths

A point of strength of the research was the range in the job roles and level of experience of the participants, with four "carers", two "team leaders", two nurses and one care home manager taking part in the study. This sample still met the homogeneity requirements of interpretative phenomenological analysis (Smith et al., 2009) as all participants had the shared experience of working in a direct care capacity with people with dementia and behaviours that challenge. However, the variety in job roles within this remit provided an opportunity for some potential diversity within the participant accounts. It was not clear if this diversity manifested in differences in the accounts elicited however.

Limitations

The primary limitation that I identified in the current research study was all nine participants having been recruited from three residential care homes. This could have affected the analysis if staff teams within those care homes had, through peer discussions, developed shared narratives of beliefs and attributions about dementia and the challenging behaviours of the residents. This was something that occurred to me while conducting interviews when I noted some similarities in the language used by different participants and reflected on why this might have been the case. The particular example that triggered this thought was two participants from the same care home both saying "if [resident(s)] knew what they were doing, they/he would be mortified". It struck me as interesting that they had both used almost identical phrasing and the specific word "mortified".

However, several other participants also made similar statements, with one participant from a different care home also using the word "mortified", which led me to conclude it was unlikely that this was a significant limitation. Further, while conducting the analysis I noted differences between accounts by participants from the same place of work. For example, the participants Brendan[1] and Rose were recruited from the same care home but seemed to have different approaches to making sense of challenging behaviours. Brendan did identify some triggers for challenging behaviours but also stated several times that at times behaviours occurred for "unknown reasons". Rose identified a variety of possible causes and triggers for challenging behaviour and gave the sense that she believed the cause could be known. Additionally, the nine participants were evenly distributed among the three care homes, which is further reason to believe any effect of this limitation will have been minimal.

On reflection, I could have been more thorough in seeking out participants from a wider range of care homes in order to increase the variation in the data collected. I had been

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[1] All participants were allocated pseudonyms

in contact with a fourth care home, however as I had difficulty reaching the manager to follow up on my initial contact and was successful in recruiting adequate numbers of participants from the other locations I did not pursue this further.

A further limitation was that all participants were accessed through initial contact with care home managers. While it is entirely possible that this had no bearing on which staff took part, it could be suggested that managers might have approached staff members whose attitudes towards the residents and perspective on their job would reflect well on the care home, rather than anyone managers felt would have expressed different, possibly more negative or derogatory views. I do not feel that this was a particular problem, as some of my participants did feel able to express negative views about their work. The nature of the interview as being confidential was stressed, which I hope will have empowered my participants to feel able to be honest about their experiences.

Directions for Future Research

Some possibilities for future research were proposed. The most noteworthy finding from the current research study was the apparent variation in attributions made by care staff about the level of impairment of residents depending on the context. This could be explored further, for example by using an independent measure of residents' level of impairment and comparing this with the attributions made by care staff about that individual. There would be ethical considerations to this as the people with dementia might not have the capacity to consent to their information being made available to the researcher or used in the study, so care would need to be taken. People with dementia may value being involved in an inclusive way in research (Sottish Dementia Working Group Research Sub Group UK, 2014). However, it is unlikely that even with appropriate adaptations to communication people with the severity of dementia of those referred to in the current study would be able to take part or

consent for their information to be included in a research project. In instances where individuals lack the capacity to give consent, fully informed consent should be obtained from a proxy (British Psychological Society, 2014). In the case of people in a dementia care setting this would most likely be their spouses or children.

The present research found that care staff experience a high level of stress, similar to symptoms of general anxiety, in their work role. I feel it would be useful to explore the use of evidence-based stress reduction techniques in dementia care staff to examine any positive effects this might have on staff experiences of their work. There is some precedent in the published research literature for this. McConachie, McKenzie, Morris and Walley (2014) examined the effectiveness of an acceptance and mindfulness-based stress management intervention on the psychological wellbeing of support staff working with people with learning disabilities and challenging behaviour. Their intervention was based on the core principles of Acceptance and Commitment Therapy, and was delivered as a full day workshop, which included didactic teaching, group discussion and practical exercises such as mindfulness, with a half day refresher after six weeks and mindfulness exercises given as homework in between sessions. They found significantly lower levels of distress in the intervention group compared to a control group, a difference which at six week follow up was largely maintained (McConachie et al., 2014).

Further Reflections on the Research Process

Timeline of the Research

The timeline of the literature review (see Section 1) and the research study (see Section 2) was that I conducted these elements in parallel.

Conducting the papers in parallel meant that one did not inform the other. Some researchers might choose to carry out the literature review first. One advantage of this could

be that the researcher would have a more thorough knowledge of the research base and therefore could be more confident that they would not neglect to ask their participants about any important issues on the topic of interest. On the other hand, the researcher then runs the risk of having fixed preconceptions about the topic area. These preconceived ideas carry the potential to bias the focus of the research paper. Additionally, in a qualitative research study there may be a greater chance of the analysis and results being biased. These issues have been debated by researchers, and it has been argued that reviewing the literature prior to conducting a research study can be of benefit and that with the use of reflexivity the researcher can minimise the risk of this prior knowledge affecting their data collection and analysis (Dunne, 2011; McGhee, Marland & Atkinson, 2007)

While I cannot know if I would have planned my research study differently had I conducted my literature review before doing so, I did not identify any important issues that were not included in my interview schedule. If I were to do a similar project in the future, I think that I would prefer to conduct my literature review before finalising the details of the research study. However, I would be aware that this approach may require me to take additional care not to allow my preconceptions to bias my interview questions, analysis and results.

Therapist vs. Clinician

From my first participant interview, I found myself feeling conflicted about my interviewing style. As a researcher, I knew that I wanted to focus on my participants' account of their experiences and allow that to be the primary guiding force in the content of the interview. However, as a therapist, I found myself automatically using some of the basic communication skills that are part of my clinical practice, such as empathising and summarising and reflecting back what the person in front of me has said. I discussed this

conflict with my research supervisor and we agreed that it was helpful to be aware of this so I could limit the extent to which I might risk reframing things my participants said. Given the emotional content of some of the experiences my participants were recounting to me however, it would have felt incongruous to avoid or limit empathetic responses in my interviewing style, and my supervisor and I agreed that this could facilitate rapport within the interview.   I wanted my participants to feel "heard", and felt that these basic listening skills were the most effective tool at my disposal to achieve this.

This conflict, between the role of a therapist and that of a researcher, has been described as being a "double agent", a situation that can lead to confused identities and may lead the individual to move towards the role they feel most comfortable in (Yanos & Ziedonis, 2006). For me, I was aware that I felt more comfortable in my role as therapist and found it necessary to consciously keep my "researcher hat" on during my interviews. These roles have different functions: in a therapy session, the aim is to work on building a long term relationship with the client for the purpose of facilitating change for the client; in a research interview the aim is to gain information from the participant (Thompson & Russo, 2012). During research interviews, it is necessary for the researcher to make the participant feel comfortable in order that they are willing to open up about their personal experiences and the quantity and quality of the data obtained is partly dependent on the relationship that develops between the participant and researcher (Karnieli-Miller, Strier & Pessach, 2009), with any findings recognised to be a function of this relationship (Larkin, Watts & Clifton, 2006). Developing a rapport with participants which leads to a sense of empathy is considered to be helpful in this process, and some level of communication skills will be required to achieve this (Thompson & Russo, 2012).

Feeling Grateful

While recruiting my participants, I benefitted greatly from three care home managers who were extremely interested in my research project. These managers actively supported my recruiting participants from their places of work, encouraging members of their staff who were interested in taking part to feel able to do so during work time. I found that I needed to follow up with the managers as they had many demands on their time and were generally unable to find the time to contact me, but when I did so they directed me towards members of staff who were interested in taking part in my research and arranged for me to come to the care home at a time when these people would be on shift and able to take time out to talk to me.

My awareness of the role this support played in my recruitment led me to reflect on how easily it could have been much more difficult for me to recruit participants had I not had this help. This is particularly in light of the findings from my own research that care staff have a number of demands on their time at work (see Section 2). I envisaged that had I been reliant on care staff finding the time at work to read my information sheet, consider taking part, contact me, and then without manager support to participate in work time presumably sacrifice a lunch break in order to meet with me, I would have had great difficulties with recruitment.

This links back to the limitations of my research study as this increased my reliance on care home managers for recruitment and so opened the possibility of them selecting to which members of staff they provided the study information.

Impact of Results on Personal Assumptions and Clinical Practice

When I began planning this research project, I anticipated that the emotional experiences staff would describe would be primarily negative and that all staff would

experience a high level of stress and emotion and work. This assumption was challenged when I read published research, for example the findings of Lambrechts and Maes (2012) that staff working with people with learning disabilities and challenging behaviour experienced both positive and negative emotional experiences in their work. I realised that it would be important for me to give my participants space to name and explore any positive emotional experiences they had relating to their work with challenging behaviour in a dementia care environment. My assumptions were further challenged by my finding that not all of my participants described the level of emotion I was expecting, and some gave an account of not being greatly affected by emotional reactions to their work.

Conducting this research study has had an impact on my clinical practice currently and also on my thoughts about my future practice. I found that I had underestimated the level of demand under which care staff in a residential care setting would be. My current clinical placement is in a learning disability service and while I had thought myself able to draw on my own past experience as a support worker when working with support staff to understand their point of view, I feel more able to do this now. This is something I have been able to discuss in supervision with my placement supervisor. As one of my preferred careers involves working in an older adults setting, I feel more able to recognise the demands that care staff in this setting face, which will be of benefit when I come to work with people who are in this job role.

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Section 4: Ethics Proposal

Ethics Proposal

Helen Lewthwaite

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

<u>Instructions</u>

1. Apply to the committee by submitting

   ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) **_and_** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: <u>LU Ethics</u>

   ✓ The completed FHMREC application form

   ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)

   ✓ All accompanying research materials such as, but not limited to,

      1) Advertising materials (posters, e-mails)
      2) Letters of invitation to participate
      3) Participant information sheets
      4) Consent forms
      5) Questionnaires, surveys, demographic sheets
      6) Interview schedules, interview question guides, focus group scripts
      7) Debriefing sheets, resource lists

2. Submit all the materials electronically as a **<u>SINGLE</u>** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (<u>http://www.lancs.ac.uk/shm/research/ethics/</u>).

3. Submit one <u>collated</u> and <u>signed</u> paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.

4. Committee meeting dates and application submission dates are listed on the research ethics committee website <u>http://www.lancs.ac.uk/shm/research/ethics</u>. Applications must be submitted by the deadline stated on the website, to:

   Diane Hopkins
   Faculty of Health & Medicine
   B03, Furness College
   Lancaster University, LA1 4YG
   <u>d.hopkins@lancaster.ac.uk</u>

5. Attend the committee meeting on the day that the application is considered.

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1. Title of Project:
An exploration of the emotional experiences of staff working with challenging behaviour in a dementia care setting

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2. If this is a student project, please indicate what type of project by ticking the relevant box:

☐ PG Diploma ☐ Masters dissertation ☐ MRes ☐ MSc ☐ DClinPsy SRP

☐ PhD Thesis ☐ PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being ☐ MD **X** DClinPsy Thesis

☐ Special Study Module (3rd year medical student)

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3. Type of study

X Involves direct involvement by human subjects

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☐ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information
4. Name of applicant/researcher: Helen Lewthwaite
5. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

6. Contact information for applicant:
 	
   E-mail: h.lewthwaite@lancaster.ac.uk   Telephone: 01524 592970
 	
   Address: Clinical Psychology, Faculty of Health and Medicine, Furness College, Lancaster University

7. Project supervisor(s), if different from applicant:
 	
   Name(s): Dr Jane Simpson and Dr Beverley Clack
 	
   E-mail(s): j.simpson2@lancaster.ac.uk and Beverley.Clack@lancashirecare.nhs.uk

8. Appointment held by supervisor(s) and institution(s) where based (if applicable): Dr Jane Simpson, Research Director (DClinPsy) and Senior Lecturer, Clinical Psychology, Division of Health Research, Furness College, Lancaster University Dr Beverley Clack, Clinical Psychologist, Lancaster and Morecambe Community Mental Health Team, Lancashire Care NHS Foundation Trust/ Adult Community, DeVitre House, Ashton Rd, Lancaster
9. Names and appointments of all members of the research team (including degree where applicable) (see above)

The Project **NOTE:** In addition to completing this form you must submit a detailed research protocol and all supporting materials.
10. Summary of research protocol in lay terms (maximum length 150 words). Individuals who have dementia may present with challenging behaviour, which by definition has a negative impact on the wellbeing of the person. This behaviour may also impact on those around them, which includes care staff. The aim of the current project is to explore the emotional experiences of care staff who work with challenging behaviour in a dementia care setting. In order to do this, interviews will be conducted with staff from care homes and the data analysed using interpretative phenomenological analysis.

11. Anticipated project dates

        Start date: October 2014   End date: May 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

The participant sample is to be care staff who work in care homes with residents who have dementia and who present with challenging behaviour. For inclusion, staff must have worked in this direct caring role with people who have dementia and behaviours that challenge full time for six months (or equivalent level of experience). Staff who do not have this level of experience will be excluded from inclusion in the study. There are no exclusion criteria based on education level.
The aim is to recruit a minimum of 6 participants and a maximum of 12. Participants will be over 18 years of age.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited from residential care homes. Participants will be recruited by being informed of the study (directly or through their manager) by the field supervisor or main researcher. This will be using the participant information sheet to provide information about the study, along with verbal discussion to provide the opportunity to ask questions. The participant information sheet includes contact information for the main researcher and project supervisors if anyone wishes to ask questions following this contact. From this point, contact will be by telephone, email or face to face. The main researcher will follow up with care homes who have been contacted about the study to check if any staff wish to take part in the study.
Staff will be able to contact the main researcher directly to express interest and arrange to take part, without their manager's knowledge if they choose. Interviews may take place at participants' place of work. However, in order for participants to take part without their manager's knowledge, the alternative interview location of Lancaster University will be offered. It is likely that if participants wish to take part without their manager's knowledge, this would need to be in a lunch break or outside of their working hours. It is expected that participants' working pattern will involve shifts, and therefore that a time could be agreed that is within the main researcher's working hours.
The field supervisor will not be aware of which staff have contacted the main researcher or agreed to take part, or from which care home, in order to preserve participants' anonymous participation.

14. What procedure is proposed for obtaining consent?

Potential participants will be able to decide whether they wish to meet with the main researcher.
At the arranged meeting, informed written consent will be sought. First the main researcher will present the participant information sheet and use it to ensure the staff member is aware of and understands the information on it. Written consent will be obtained using the consent form if the staff member agrees to take part in the study.
Participants will be able to withdraw from the interview at any point if they wish to do so; this will be made clear from the participant information and consent form. Participants will also be able to withdraw after the interview has taken place, however it will be made clear that when their data have been anonymised and incorporated into the analysis it may not be possible for them to be withdrawn.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

It is possible that recalling the emotional impact of what may be a challenging part of their work will cause some psychological distress to participants. Participants will be offered the opportunity to discuss this with the main researcher at the time of the interview. Participants will be directed to seek support from their line manager if they wish, who may be able to offer support with work-related matters. It is acknowledged that participants may prefer not to do this if they do not wish their manager to know they have taken part in the study as this would compromise their anonymous participation. However, participants would be given the choice of whether to use this option.

It may be possible for participants to make use of other sources of support at their place of work such as through occupational health if their organisation provides it; this would be discussed with them at the time if they were experiencing distress.

Participants' General Practitioners might be an appropriate source of support, as they would be able to offer advice, referral or signposting to relevant services, or support with an absence from work if required.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

It is possible that talking to participants about potentially distressing work situation could cause some psychological distress to the researcher. If this is the case the researcher will seek support from the project supervisors. If potential malpractice is uncovered, this may be a difficult situation for the main researcher. If this happens the researcher will use the support of the project supervisors and seek guidance from them on how to proceed.

It is acknowledged that travelling to and conducting interviews alone may come with some risk; the main researcher will refer to the Lancaster University Lone Working Policy.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

No direct benefits to participants have been identified.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

None.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

The data will be collected using individual semi-structured interviews, which will be guided using an interview schedule (Appendix 1 of the study protocol). This is to allow the data collection to be guided by participants' experiences.

The transcribed interviews will be analysed using interpretative phenomenological analysis. Interpretative phenomenological analysis is a qualitative research method which aims to make sense of participants' stories and to then understand these from a psychological perspective. This was considered to be appropriate for the aims of this study, which looks to understand the emotional experiences of the participants.

As is common in interpretative phenomenological analysis, this will be an iterative process involving several stages, with the main researcher revisiting and refining notes on the transcript to form themes which are then further developed as part of the analysis. The main researcher will carry out this analysis independently, with guidance from the academic supervisor on the process as required.

The academic supervisor will have access to audio recordings, which will be played during meetings with the main researcher. Participants will not be identifiable to the academic supervisor. The academic supervisor will not have copies of these files. The academic

supervisor will also have access to anonymised transcripts, which will be in the form of printed copies that will be returned to the main researcher. No copies will be kept by the academic supervisor or electronic files shared.

The field supervisor will not have access to audio files or transcription files. However the field supervisor will make comments on the credibility of the analysis on the basis of selected anonymised quotes.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

A member of the Lancaster University LUPIN involvement network was present at a meeting to present and discuss the initial idea for the project. This person gave their opinion on the relevance of the project idea, as well as sharing concerns over possible issues with recruitment which were taken into account when further developing the project proposal.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Digital audio recordings of interviews will be transferred from the recording device to a secure server (the Lancaster University server) at the first opportunity, following which they will be deleted from the device by the main researcher. The audio files will be played during meetings with the academic supervisor, however participants will not be identifiable and no copies of files will be kept by the academic supervisor. The audio files will be kept on the secure server until the project has been submitted in case they are needed for reference. When the project is complete the files will be deleted by the main researcher.

Interviews will be transcribed by the main researcher. The transcription files will be anonymised by removing any information that could identify participants. Transcription files will be stored on a secure server. Only the main researcher will have access to them, however these may be shared with the academic supervisor for the purposes of supervision. This would be done by using a printed copy of the transcript, which the academic supervisor will return to the main researcher. No copies will be kept or files transferred.

When the study is complete, these transcription files will be encrypted by the main researcher and stored electronically by the Doctorate in Clinical Psychology administration team, along with scanned copies of the consent forms. The encrypted files will be transferred securely using the ZendTo file transfer software. The files will be deleted by the DClinPsy admin team responsible for storing them ten years after submission of the project, as per department guidance.

22. Will audio or video recording take place?   ☐ no   **X**audio   ☐video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Digital audio recordings of interviews will be transferred from the recording device to a secure server (the Lancaster University server) at the first opportunity, following which they will be deleted from the device. The audio files will be deleted from the secure server when the project has been submitted.

23. What are the plans for dissemination of findings from the research?

The research will be written up as part of the main researcher's DClinPsy Thesis submission. The final research report may be submitted for publication.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice

from the FHMREC?

It is acknowledged that participants may not feel comfortable with their line manager being aware of their participation in the study. This may therefore make it difficult to hold interviews at participants' workplaces. If this does cause difficulty, an alternative meeting place (such as at Lancaster University) will be offered.

If participants do travel to Lancaster University for interview, their travel costs can be reimbursed, up to a maximum of £20 per participant interview, in accordance with DClinPsy policy. If participants travel by car, they will be reimbursed at the rate of 45p/mile. If participants travel by public transport, they will be reimbursed when they can provide a receipt/ ticket. Reimbursement may take place at the time of interview, with the main researcher collecting money from the DClinPsy Research Coordinator and participants signing a receipt to confirm they have received payment for their expenses. If it is not possible to refund expenses at interview, participants will be provided with a copy of the Lancaster University business expense claim form and a freepost envelope to return it to the department along with any receipts/tickets.

Project outcomes will be published in a way that ensures anonymity for participants.

Participant confidentiality may have to be broken where the researcher considers that a participant has indicated that they may cause harm to themselves or others. This is included on the participant information sheet and consent form.

Signatures: Applicant: ……………………..…………………...

                      Date: …………………………………………...

                      Project Supervisor* (if applicable): ………………………………….................

                      Date: …………………………………………...

   *I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Appendix A

Research Protocol

Title: An exploration of the emotional experiences of staff working with challenging behaviour in a dementia care setting

Version 3

Helen Lewthwaite, Trainee Clinical Psychologist, Lancaster University

Academic supervisor: Dr Jane Simpson, Faculty of Health and Medicine, Lancaster University

Field supervisor: Dr Beverley Clack, Clinical Psychologist, Lancaster and Morecambe Community Mental Health Team, Lancashire Care NHS Foundation Trust

Introduction

"Dementia" is an umbrella term which describes a progressive loss of cognitive abilities including memory function, due to a degenerative disorder. Many causes of dementia exist, with the most common being Alzheimer's disease (Stokes, 2000). Dementia can affect people of any age but most commonly affects older people. People with a diagnosis of dementia are most often supported to live at home by carers in their family or social networks, though some people become unable to live at home and it can then be necessary for them to live in a residential care settting (Stokes, 2000).

The previously mentioned loss of cognitive abilities in dementia can lead to a number of difficulties, one of which is challenging behaviour (James, 2011). Challenging behaviour, also referred to as behaviours that challenge, is most often described as actions by a person that negatively impact on their wellbeing as a result of the distress they cause; this distress may be physical or psychological (James, 2011). Examples of challenging behaviour include verbal and physical aggression, sexually inappropriate behaviour and self-harm (James, 2011). Some of these behaviours carry a potential risk either to the person themselves or to those around them, which may include family members, fellow residents or care staff.

The way in which such behaviours are responded to and managed by care staff could be suggested to have an effect on the level of distress experienced by the individual. One determinant of response to a behaviour is an understanding of its cause. Weiner (1980) suggested a model of helping behaviour, in which when an event (or behaviour) occurs,

people make attributions about the cause. These attributions, along with associated emotional reactions, can determine the person's response. This model has been suggested to apply to staff responses to challenging behaviour. It places importance on the role of emotions in determining response, for example if a member of staff understands the cause of a behaviour as internal, controllable and stable, they may be more likely to feel angry and have less optimism for the person's behaviour changing (Rose & Rose, 2005; Stanley & Standen, 2000).

There has been some research into the area of staff emotional responses to challenging behaviour and how these may be linked to attributions. The great majority of this research has been conducted in the area of intellectual disabilities. In the area of challenging behaviour in dementia, Parker et al. (2012) found that additional cognitive demands (as may be expected in a care home setting) may lead to individuals attributing greater control to the person displaying challenging behaviour. Some support has been found for the applicability of Weiner's model in the setting of challenging behaviour in dementia, particularly related to the role of emotions in affecting staff responses to behaviour (Todd & Watts, 2005). The research that does exist has been conducted using quantitative research methods.

The aim of the proposed study is to explore the emotional experiences of care staff who work with individuals who have dementia and who present with behaviours that challenge in a residential care setting. Attributions about challenging behaviours will also be explored. This will be done using a qualitative methodology, specifically interpretative phenomenological analysis. It is considered that this research method will best enable the first-hand accounts of staff, gathered through interviews, to inform the findings of the study.

Method

Participants

The proposed participants are staff who work in a carer role in registered care homes where some of the residents have dementia and present with behaviours that challenge. To ensure participants have an appropriate level of experience in this setting, staff who have worked in this carer role (which involves working in a direct care capacity) for at least six months full time (or equivalent) in the setting of residential care, where the residents included people with dementia who present with challenging behaviour, will be eligible for inclusion in the study. There are no exclusion criteria based on education level. It is expected that the staff eligible for inclusion will be in jobs with titles such as carers, care assistants or nursing

auxiliaries, roles which do not involve specialisation and do not require a specific education, although some may have completed relevant NVQ courses at college. The aim is to recruit at least 6 and up to 12 participants who have the shared experience of working in a direct care capacity in this setting.

Design

A qualitative methodology is proposed. Individual semi-structured interviews will be used to collect data. Interpretative phenomenological analysis will be used to analyse the data. Interpretative phenomenological analysis is a qualitative research method which aims to make sense of participants' stories and to then understand these from a psychological perspective (Larkin, Watts & Clifton, 2006).

Materials

An interview schedule will be used to guide topic areas for participant interviews (see Appendix B).

Procedure

Potential participants will be identified by the field supervisor, who will liaise verbally with care home managers to identify care homes where the manager is happy for their staff to take part in a research project. The main researcher will then arrange to meet with care home managers and/ or potential participants to provide information about the study using the participant information sheet (in care homes where the manager has agreed for the research to take place in the home). The main researcher's contact details will be provided so that staff can ask for more information or request to take part if they choose, and so that they can do this directly without their manager knowing who has contacted the researcher. The main researcher will follow up by arranging to go into care homes and speak to staff and/ or care home managers directly to find out if any staff wish to take part in the study. Again staff will have the opportunity to express interest without their manager's knowledge.

The interviews will take place at the participants' places of work. If this presents difficulties with preserving participant anonymity due to managers being aware of which staff are taking part, the alternative meeting place of Lancaster University will be offered. Prior to each interview commencing, full consent will be obtained by using the participant information sheet to ensure the participant understands the nature of the study, what will be done with

their recorded interview and transcribed data and their right to withdraw. A consent form will be used to obtain signed consent at this point. It will be made clear that if participants contact me to withdraw after the interview has taken place, if their data have already been anonymised and included in the analysis it may not be possible to remove them. The interview schedule will be used to guide each interview.

Proposed analysis

The interview data will be analysed using interpretative phenomenological analysis. This qualitative research method can be used to explore participants' experiences, focussing on the perspective of participants and how they make meaning from their experiences. It is recognised that the researcher's perspective will play a role in the construction of the account (Larkin et al., 2006). The aim is to then interpret this account in relation to wider context, including psychological theory, remaining focussed on the participants' own experiences and how they make sense of these.

Practical issues

Interviews will be recorded using a digital audio recorder. As soon as possible after each interview, the audio file will be transferred onto a secure server (Lancaster University server) and the file deleted from the portable device. These files will be shared with the academic supervisor by playing the file in supervision; the academic supervisor will not have copies of these files and participants will not be identifiable. When the project has been submitted, the audio files will be deleted from the server by the main researcher.

The files of the transcribed interviews will be anonymised and stored on the secure server. Only the main researcher will have direct access to these files; they may be shared with the academic supervisor only for the purposes of research supervision. This would be done using printed copies of the anonymised transcript, which would be returned to the main researcher at the end of each supervision meeting. No copies will be kept by the academic supervisor or electronic files transferred. Following project completion, the anonymised transcript files, and the scanned consent forms, will be encrypted by the main researcher and securely transferred to the Doctorate in Clinical Psychology administration team using ZendTo file transfer software. They will then be stored electronically for a period of ten years, following which they will be deleted by the DClinPsy administration staff responsible for storing them.

Ethical concerns

It is possible that recalling emotional responses to situations which may have been challenging or distressing for the participants at the time will cause some level of distress. Before and after each interview the researcher will acknowledge this. As a trainee clinical psychologist, the main researcher will be able to be sensitive to any distress participants are experiencing while signposting to appropriate sources of support. Participants may choose to seek support from their line manager, although in doing so would accept that this would compromise their anonymous participation. Participants may have access to occupational health through their organisation, which would be a possible source of support. Participants' General Practitioners would be able to offer signposting or referral to other services, as well as support with a period of absence from work if this was required.

In talking about participants' working practice, it is possible that participants will say something which causes concern relating to their own or someone else's practice. Although the participants will be employees of private sector organisations, the residents' needs are met by Lancashire Care NHS Foundation Trust and so I will adhere to their policies. If it is considered that the risk is immediate, I would inform a senior member of staff in the care home to ensure immediate safety of residents. Following this, or if I believe the person to be safe, then I will immediately contact my field supervisor, Dr Beverley Clack. She and I would work together in line with Lancashire Care NHS Foundation Trust policy around safeguarding adults, including sharing of information and escalating appropriately within the Trust. This would include contacting the local Safeguarding Lead for vulnerable adults to discuss how the information should be shared.

Timescale

Data collection will begin when ethical approval has been obtained, which is anticipated by October 2014, and will continue until the end of December 2014.

The final report will be written by May 2015, when it will be submitted as part of the assessment process for the Doctorate in Clinical Psychology. Following this it is anticipated that the report will be submitted for publication in a peer-reviewed journal.

References

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Parker, S., Clarke, C., Moniz-Cook, E., & Gardiner, E. (2012). The influence of 'cognitive busyness' on causal attributions of challenging behaviour in dementia: A preliminary experimental study. *Aging & Mental Health, 16*(7), 836-844

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Weiner, B. (1980). A cognitive (attribution)-emotion-action model of motivated behaviour: an analysis of judgements of help-giving. *Journal of Personality and Social Psychology, 39*(2), 186-190

Appendix B

Interview Schedule

- Can you tell me about the different types of people who live in the care home?

- What does the term "dementia" mean to you?

- What does the term "challenging behaviour" mean to you?

    o   What types of behaviours do you think would be described as challenging?

        (Prompt if participant appears unsure/ does not list many different behaviours)

- What do you think leads to people with dementia presenting with challenging

    behaviour?

- Can you think of some examples of challenging behaviour from residents who have

    dementia?

    o   How did you respond?

    o   Why do you think the person acted in that way?

    o   How did those incidents make you feel? / What sort of emotions were brought

        up for you?

    o   Follow up: How was it at the time? Immediately after? What about now?

- Are there any types of challenging behaviour that are more difficult to work with?

- How does working with challenging behaviour impact on you?

Appendix C
Participant Information Sheet

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Participant Information Sheet

An exploration of the emotional experiences of staff working with challenging behaviour in a dementia care setting

My name is Helen Lewthwaite and I am conducting this research as a Trainee on the Doctorate in Clinical Psychology at Lancaster University, Lancaster, United Kingdom. This research project is part of my thesis for my course.

What is the study about?
The purpose of this study is to talk to care staff who work with residents who have dementia and present with challenging behaviour, to get an idea of what their experiences are of the emotional impact of this work.

Why have I been approached?
Care staff who have worked in a residential setting with people who have dementia and challenging behaviour for more than 6 months are being approached to take part.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?
If you decide you would like to take part, you would be asked to meet with me. This would most likely be at your usual place of work, but if you would prefer to meet elsewhere we could meet at Lancaster University. This interview would take around 45 minutes to 1 hour, and involve having a conversation about your work with challenging behaviour in dementia and any emotional impact this may have had on you.
You will have the opportunity to withdraw from the interview at any point if you wish. If you do withdraw during or immediately following your interview, none of your data will be kept. You may still contact me to withdraw from the study after the interview has taken place, however once your data have been anonymised and incorporated into my analysis it might not be possible for me to remove them, although I would make every effort to do so up until the point of my project being submitted.

Will my data be confidential?
The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to these data:
  o Audio recordings will be transferred to a password-protected computer as soon as possible after interviews, following which they will be deleted from the recorder. I will be the only person with direct access to the files. I might play the recording for my academic supervisor, however you would not be identifiable and she will not have

a copy of the file. I will delete the audio files after the project has been written up and submitted to Lancaster University as part of my assessment.

o The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

o The files containing the interview transcript will be stored on a secure server (the Lancaster University server). I may show these to my academic supervisor, but you will not be identifiable.

o Following completion of the project, the Doctorate in Clinical Psychology administration team will securely store an encrypted electronic file of your anonymised interview transcript for a period of ten years, following which it will be deleted.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisors and possibly your manager about my concerns. If possible, I will tell you if I have to do this.

What will happen to the results?
The results will be summarised and reported as part of a submission for my university course. They may also be submitted for publication in an academic or professional journal.

Are there any risks?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. Authorisation has been received by your managers.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:

Helen Lewthwaite
Trainee Clinical Psychologist
Faculty of Health and Medicine
Furness Building
Lancaster University

h.lewthwaite@lancaster.ac.uk

Telephone: 07508 406274

Or one of the project supervisors:

Dr Jane Simpson
Academic Supervisor
Faculty of Health and Medicine
Furness Building
Lancaster University
j.simpson2@lancaster.ac.uk

Dr Beverley Clack
Field Supervisor
Clinical Psychologist
Lancaster and Morecambe Community Mental Health Team
Lancashire Care NHS Foundation Trust/ Adult Community
DeVitre House
Ashton Road
Lancaster LA1 5AL
Beverley.Clack@lancashirecare.nhs.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not
want to speak to the researcher, you can contact:

Professor Susan Cartwright Tel: (01524) 592430
Head of Department   Email: s.cartwright@lancaster.ac.uk
Division of Health Research
Lancaster University

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme,
you may also contact:

Professor Roger Pickup
Associate Dean for Research   Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
Lancaster University

Thank you for taking the time to read this information sheet.

Resources in the event of distress
It is possible that taking part in this research will cause you to feel distressed. Should this
happen, you may find the following resources useful:

- You may wish to speak to your line manager for support. This would mean them
  being aware that you have taken part in my research so you would need to decide if
  you are happy with them knowing this.
- If you have access to occupational health support through your organisation, this may
  be helpful.
- Your GP would be able to direct you to other services or refer you for further support
  if you need it.

Appendix D

Consent Form

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Consent Form

Study Title: An exploration of the emotional experiences of staff working with challenging behaviour in a dementia care setting

We are asking if you would like to take part in a research project aimed at understanding the emotional experiences of care staff working with people with dementia who also show challenging behaviour. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form, please speak to the principal investigator, Helen Lewthwaite.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what my involvement within this study will be. ☐

2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3. I understand that my interview will be digitally audio recorded and then made into an anonymised written transcript. ☐

4. I understand that digital audio recordings will be kept until the research project is submitted to Lancaster University as part of the main researcher's thesis (expected to be May 2015). ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for them to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

7. I consent to information and anonymised quotations from my interview being used in reports, conferences and training events. ☐

8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with appropriate others. ☐

9. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

10. I consent to take part in the above study.

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix E

Ethics Committee Approval Letter

Research and Enterprise
Services Division

Lancaster
University
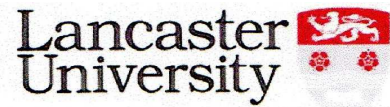
Applicant: Helen Lewthwaite
Supervisor: Dr Jane Simpson
Department: DHR

01 December 2014

Dear Helen and Jane,

Re: An exploration of the emotional experiences of staff working with challenging behaviour in a dementia care setting

Thank you for submitting your amendment for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The amendment was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this amendment.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C.Taylor

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Roger Pickup (Chair, FHMREC)