

**Promoting Cognitive Security among People with Dementia
through Empathy, Person-centred Attitudes and a
Compassionate Approach**

by

David Pulsford

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of Philosophy by Published Work at the University of Central Lancashire

Month/year (month/year of final approval by examiner(s))

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I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution

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David Pulsford

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ABSTRACT

Background: Current thinking regards person-centred care as being the most appropriate approach for people with dementia. This requires carers to possess high-level interpersonal skills and personal qualities.

Aim: This thesis presents a three-component model of the personal qualities that carers should possess in order to manifest person-centred care for people with dementia.

Method: The model represents a synthesis of ideas derived from my published work, which includes an ethnographic analysis of Woodlands Therapy, a small-group sensory-motor activity for people with moderate to advanced dementia and a mixed-method study of nursing and care staff's attitudes towards and responses to aggressive behaviour by people with dementia living in care homes. The synthesis was informed by literature from social psychology and medical ethics that proposes an 'empathy – attitudes – action' framework for helping qualities.

Results: The model has at its heart 'Cognitive Security' as the goal of dementia care. In order to achieve this, carers need the qualities of Empathy, Person-centred Attitudes and a Compassionate Approach. In the thesis I define and identify the components of these qualities and justify their value through findings from my published work and related literature.

Discussion: My model has implications for dementia care practice, through encouraging practitioners to reflect on their own personal qualities; for education and training, through highlighting priorities for courses for both professional and lay carers; for policy, through contributing to the debate regarding the relative importance of resources and personal qualities in improving care for people with dementia and for research, through testing the model and exploring resulting areas of enquiry.

Conclusion: This is the first time that a tripartite 'empathy – attitudes – action' framework has been applied to the qualities needed by carers of people with dementia. As such, my model makes an original contribution to knowledge in this field.

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This thesis is dedicated to the late Irene Connor.

SECTION 1 - INTRODUCTION

For years, traditional thinking regarded dementia as simply a function of neurological disease that progressively destroyed the person's cognitive and social abilities and diminished their personhood (Minski, 1972). The loss of personhood implied that care for people with moderate or advanced dementia need go no further than physical safety, cleanliness and nutrition and that the experience of many people with dementia in long-term care settings was little more than minimal warehousing (Evers, 1981). In the 1990s, the late Tom Kitwood developed a new culture of dementia care (Kitwood & Benson, 1995) that challenged the "standard paradigm" of dementia care (Kitwood, 1997: p.35). The new culture regarded the maintenance and enhancement of personhood and well-being as the main goals of caring for someone with dementia. Person-centred care (Kitwood, 1995) requires that carers¹ should meet psychological, emotional and social needs as much as physical needs. This implies that carers require personal and interpersonal skills and qualities as much as physical care skills. In this thesis, I discuss a three-component model of the fundamental qualities that carers should ideally possess in order to manifest person-centred care for people with dementia. These qualities are empathy with the person, person-centred attitudes and a compassionate approach. The demonstration of these qualities by a carer will promote a concept I refer to as 'cognitive security' in the person with dementia, which in turn should enhance the person's sense of well-being. My model is outlined in Figure 1 and in the remainder of this thesis I will define and discuss in detail its components and seek to justify their inclusion from findings and insights within my published work and related literature.

¹ I will use the terms "professional carer(s)" or "staff" when referring to professional care staff (nurses and care assistants/support workers) and "family carers" for those who undertake informal caring activities. I will use the term "carers" when points could be applied to either professional carers or family members.

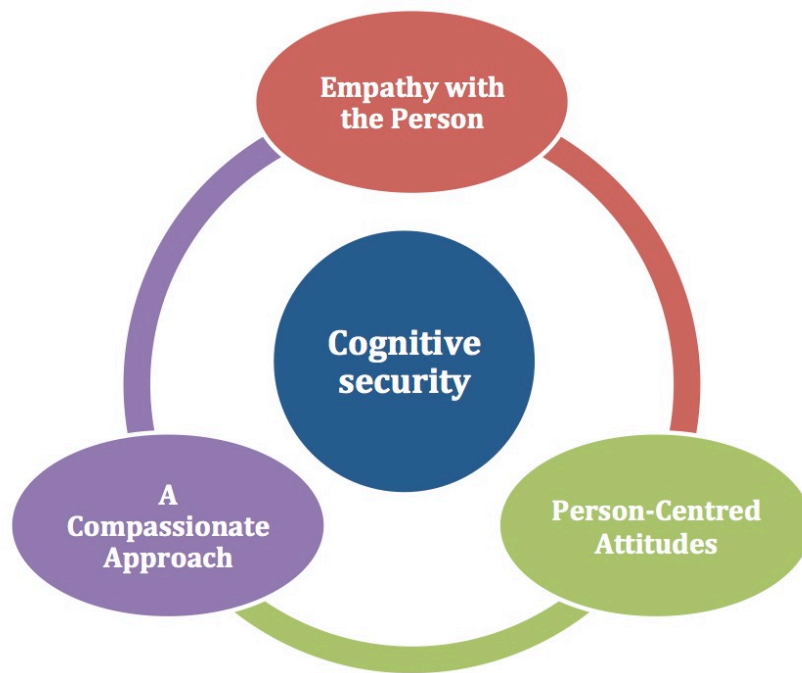


Figure 1: A model of the three fundamental qualities that carers should ideally possess in order to promote cognitive security.

My published work that underpins this thesis derives from the investigation of two different aspects of dementia care: the facilitation of social, diversional and therapeutic activities and the management of aggressive behaviour. The focus of both areas was the role of nursing and other care staff and the interpersonal skills and personal qualities they required to provide successful care for people with dementia. My first academic foray into the world of dementia care was a literature review and discussion paper on therapeutic activities and the role of nurses and other professional carers in facilitating such activities (Pulsford, 1997). I was particularly interested in why professional carers were often reluctant to get involved in activities - a state of affairs that still pertains (Harmer & Orrell, 2008; Bradley, 2013). The values and attitudes held by staff seemed crucial and in that paper I explored these in

relation to alternative perspectives staff may hold regarding people with dementia; their readiness to help people with dementia and their priorities for care. I concluded that attitudes such as lack of self-confidence and a lack of faith that activities were benefiting people with dementia acted as powerful constraining factors on carers.

My subsequent analysis of Woodlands Therapy² (WT), a small-group therapeutic approach for people with moderate or advanced dementia that embraced sensory-motor and play-based activities, offered a more positive perspective on carers' involvement in therapeutic activities (Pulsford, Rushforth & Connor, 1999 & 2000). The study used ethnographic methods, including analysis of videotapes of WT sessions and interviews with staff who participated in sessions. In these papers I began to consider the role of empathy as a central quality of carers. I noted that carers required a quality that I termed "cognitive empathy" (Pulsford et al., 2000: p.656) to understand the perspective of participants in WT and needed to use that understanding to decide on and facilitate activities that were understandable and engaging to participants. Empathy was also needed to judge the success or otherwise of those activities. I proposed that empathy with people with dementia was in some ways different to empathy with people not experiencing dementia, a notion explored in this thesis.

Carers' attitudes were also found to be significant, in particular in respect of their views about the aims of WT and regarding the play-based activities that formed a large component of WT. In an attempt to explain the value of play-based activities I developed the concept of "cognitive security" as a desired outcome of dementia care (Pulsford et al., 1999: p.16; Pulsford et al., 2000: p. 656). This concept is central to the model presented in this thesis. From this project I also gained insight into the communication skills and personal manner needed by nurses and other carers for successful care – ideas that have crystallised in the model presented in this thesis as 'A Compassionate Approach'.

² The term Woodlands Therapy derived from the name of the Day Hospital in which it was practiced.

Later, my interest in the management of aggressive behaviour by people with dementia began with another review and discussion paper (Pulsford & Duxbury, 2006). In this paper I discussed the nature of aggressive behaviour by people with dementia and alternative strategies for responding to such behaviour. The values and attitudes of professional carers were again highlighted as influencing both the extent of aggressive behaviour and how it is managed. It was noted that carers could sometimes trigger aggressive incidents through perceived 'bad attitudes' and the point made that in the absence of clear evidence for the effectiveness of any one strategy, carers' attitudes are likely to influence which response they choose to implement first in any situation.

I also observed that there was little research into the actual strategies used by professional carers in residential settings (Pulsford & Duxbury, 2006: p.616). This provided the impetus for my investigation of aggression management in a number of dementia care units in care homes (Pulsford, Duxbury & Hadi, 2011; Duxbury, Pulsford, Hadi & Sykes, 2013). This was a multi-method study, including a survey of professional carers' attitudes; an audit of aggressive incidents; semi-structured interviews with a sample of care staff and focus groups with relatives of residents. In this study I found that alternative attitudes towards the causes and best ways to respond to aggressive behaviour could be identified and measured, through developing an attitude rating scale named the Management of Aggression in People with Dementia Attitude Questionnaire (MAPDAQ). Factor analysis of the MAPDAQ revealed two factors that corresponded to a 'person-centred' or 'standard paradigm' view of aggression and its management (Pulsford et al., 2011: p. 99). The MAPDAQ was used to survey professional carers in care homes, finding that they leaned more towards the person-centred than the standard paradigm way of thinking. Additionally, an audit of aggressive incidents and how they were managed broadly confirmed that carers' person-centred attitudes were reflected in 'compassionate' ways of responding to aggressive behaviour, i.e. by using interpersonal means of responding before physical or pharmacological means

(Pulsford et al., 2011). These findings were supported by qualitative data from interviews with professional carers and focus groups with family members (Duxbury et al., 2013). Further analysis of the qualitative data also revealed the ability of staff and family members to empathise with residents and to display person-centred attitudes. Analysis also provided insights into how these qualities translated into a “compassionate approach” to responding to aggressive behaviour (Duxbury et al., 2013: p798).

The key components of my model were therefore present in my published work. In bringing them together, I was influenced by literature from other disciplines that integrated similar constructs. One area of influence was work in social psychology to explore the links between encouraging empathy with a member of a stigmatised group and enhanced willingness to help that person. Batson, Chang, Orr & Rowland (2002: p.1657) proposed an “Empathy – Attitude – Action” model, in which taking the perspective of a person in need leads to more positive attitudes towards that person, which in turn leads to greater willingness to assist the person. Batson et al. (2002) demonstrated that increased empathy to a stigmatised individual led to more positive attitudes and greater willingness to help other members of the group that the person represented.

The ‘Empathy – Attitude – Action’ framework was subsequently taken up by Petra Gelhaus from the perspective of medical ethics. She also proposes a three-component model of what she termed the “desired moral attitude” of a clinician (Gelhaus, 2012a; 2012b; 2013). The components she explores are Empathy, Compassion (which she regards as a “professional attitude”) and Care. She sees these three components as the manifestation of “empathic compassion” summing up her model as:

“the capacity (or skill) of empathy, the adequate professional inner attitude of the doctor (compassion) and the active side of this attitude (care)” (Gelhaus, 2012a: p105).

A similar 'Empathy-Attitude-Action' framework underpins my own model of the qualities needed by carers of people with dementia, although I have adopted different terms for these broad concepts. The influence of Batson's and Gelhaus's ideas for the development of my model will be discussed further in Section 3.

My model therefore reflects a synthesis of ideas and insights from my published work, underpinned by insights from social psychology and other related disciplines. In Section 2 of this thesis I review literature from the field of dementia care that provides evidence for the relevance of the broad components of my model. In Section 3 I provide a reflexive account of the development of my model, including how my own values, beliefs and experiences shaped the findings of the related published work, along with influences from other published sources. I present an analysis of the components of the model in Section 4, deriving points from the findings and insights within my published work and related literature. In Section 5 I will discuss the implications of my model for dementia care practice, education, policy and research.

SECTION 2 - LITERATURE REVIEW: THE RELEVANCE FOR CARE OF PEOPLE WITH DEMENTIA OF EMPATHY, PERSON-CENTRED ATTITUDES AND A COMPASSIONATE APPROACH

The aim of the literature review within this PhD by Published Work is not to provide a systematic review of the literature related to the aspects of dementia care under discussion as this would lie outside of the parameters of the award. Instead a robust approach has been taken to focus on key literature published between 1990 and 2015. The aim of the review is to provide an overview of literature specifically relevant and related to the series of published work presented and discussed in this thesis and to the model of caring qualities derived from it. Consequently, research literature related to dementia care that focuses on the relevance of empathy, attitudes and a compassionate approach to care of people with dementia was accessed.

The following databases were searched: CINAHL, MEDLINE, PsychINFO; PsychARTICLES; SocINDEX. The search terms employed were:

- Dement* OR Alzheimer*
- AND
- Empath* OR Perspective Taking
- Attitud*
- Compassion* OR Caring
- Person Centred Care

The inclusion and exclusion criteria that were established are set out in Table 1. The papers were scrutinised for methodological soundness using:

- The Center for Evidence-based Management (EDMa) Critical Appraisal of a Survey checklist <http://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Survey.pdf>
- The Critical Appraisal Skills Programme (CASP) Qualitative Research checklist http://media.wix.com/uqd/dded87_951541699e9edc71ce66c9bac4734c69.pdf

Table 1: Literature Review: Inclusion and Exclusion Criteria

Inclusion	Exclusion
<p>Written in English</p> <p>Published since 1990</p> <p>Published in a peer-reviewed journal</p> <p>Quantitative and qualitative research or review papers with a focus on dementia care</p> <p>Papers with a focus on the relevance to the care of people with dementia of attitudes and/or empathic or compassionate qualities possessed by professional or family carers of people with dementia</p>	<p>Opinion or 'how to' papers</p> <p>Papers with a focus on the empathic qualities or attitudes of people with dementia themselves</p>

2.1 Empathy as a Quality of Carers

While the importance of empathy with people with dementia has been emphasised by leading figures in dementia care (Kitwood, 1997; Stokes, 2000; Brooker, 2004), there has been surprisingly little research into empathy in carers, or the links between empathy and other caring qualities. Astrom, Nilsson, Norberg and Winblad (1990) surveyed nurses and care staff in nursing homes and long stay wards for people with dementia, using a range of quantitative measures including an empathy scale developed by LaMonica (1981) and a measure of attitudes towards people with dementia. Nurses were found to have moderately

well-developed empathy and generally positive attitudes. Unqualified staff had significantly lower empathy mean scores and less positive attitudes than qualified nurses, but for all respondents the correlation between empathy and attitudes was weak. Eritz and Hadjistavropoulos (2011), in a study of family members' perceptions of pain in people with dementia for whom they were caring, found that carers' global empathy levels, as measured by the Interpersonal Reactivity Index (Davis, 1980) did not correspond to their ability to determine whether the person for whom they were caring was in pain. On the other hand, Egan et al. (2007) explored the potential benefits of increasing professional carers' empathy with residents by sharing residents' life stories with carers, finding a subsequent decrease in residents' aggressive behaviour as carers used empathic understanding to find more appropriate care responses.

2.2 The Role of Person-centred Attitudes in Dementia Care

Much work has been done to explore professionals' and family carers' attitudes towards people with dementia and some has sought to demonstrate the effects of carers' attitudes on approaches to care. MacDonald and Woods (2005) surveyed nurses in United Kingdom nursing homes, utilising the Approaches to Dementia Questionnaire (ADQ) (Lintern & Woods, 1996). They found that those reporting more person-centred attitudes were better able to recognise cognitive impairment among residents. This suggested a link between person-centred attitudes and greater empathic sensitivity towards individuals in their care. Similarly, Zimmerman, Williams and Reed (2005) surveyed direct care staff in United States care homes, finding that those with more person-centred attitudes also reported greater perceived competence and more job satisfaction.

The exploration of attitudes of carers more specifically towards behaviour that challenges, including aggressive behaviour, reveals potential links between positive attitudes and better

outcomes of care. Bahareethan and Shah (2000) measured the attitudes of nursing staff on 'psychogeriatric' wards using a modified version of the Alienation Scale (Morgan & Stanton, 1997). They compared responses with the level of aggression displayed by patients and found correlations between staff feeling distant and alienated from patients and rates of aggressive behaviour. Nakahira, Moyle, Creedy and Hitomi (2008) surveyed staff attitudes about aggressive behaviour by people with dementia in nursing homes in Japan, using the Attitudes Towards Aggression Scale (Jansen, Middel & Dassen, 2005). Older, more experienced staff and those who were better educated reported more positive attitudes (in the sense of valuing a more person-centred approach). These staff were less likely to report using physical restraint than those with negative attitudes, although interestingly staff with more positive attitudes were more likely to report using medication as a response to aggression.

Some studies have demonstrated the negative effects of carers holding less positive attitudes. Stockwell-Smith et al. (2011) found that attitudes of staff in dementia care units in Australia owed more to "malignant social psychology" (Kitwood, 1997, p. 89) and the standard paradigm than to a person-centred philosophy. These attitudes were related to a task-orientated and controlling care regime. Sanders and Swails (2009) interviewed hospice social workers regarding working with people with dementia, finding that negative attitudes led to respondents giving low priority to people with dementia at the end of life.

Studies of carers' attitudes towards undertaking activities with people with dementia highlighted degrees of ambivalence. Hope and Waterman (2004) examined reasons for the under-use of a Multi-Sensory Environment (MSE) within an older adults' in-patient service, concluding that one factor was the attitudes of nursing staff. Staff felt insecure and lacking in understanding of how best to use the MSE and found it hard to conceptualise facilitating

MSE sessions as 'real work'. Some staff also expressed discomfort in engaging with patients in what they regarded as a childlike fashion. Hutchinson and Marshall (2000) sought the views of family carers about the use of an 'Activity Bag' with the person for whom they were caring, finding a range of positive and negative attitudes towards the components of the Activity Bag and concluding that the state of mind of the family carer was crucial for its success. For example, the carer must want to use the Activity Bag as a tool and must derive enjoyment from sharing it with the family member. Finally, Sung, Lee, Gang and Smith (2011) found that, while care home staff held positive attitudes towards the use of music as a therapeutic approach, only 30% of respondents had actually used music in their practice, citing constraints such as limited knowledge and skills, lack of resources or time.

2.3 The Value of a Compassionate Approach to Care

Studies have been carried out using different methodologies to seek insights into the role of carers' personal qualities as a factor in care. Rundqvist and Severinsson (1999) interviewed professional carers on a dementia care ward, finding that respondents regarded the most valuable aspects of their care approach to be the use of touch and positive physical contact and the possession of caring values such as consideration, patience and compassion. The theme of compassion was also prominent in a meta-synthesis of studies investigating professional carers' perceptions of dignity-preserving dementia care (Tranvag, Petersen & Naden, 2013). The meta-synthesis found that key aspects of care included having compassion for the person, confirming the person's worthiness, creating a humane environment and balancing individual choices against making choices for people who lacked capacity. Nolan (2006) interviewed nurses in acute hospitals, finding that respondents recognised the centrality of forming a relationship with the person with dementia as the medium in which caring is experienced. This insight was reinforced by Ericsson, Kjellstrom and Hellstrom (2011) who analysed videotapes of care encounters with people with

advanced dementia, emphasising the need for professional carers to allow those in their care to “open up” through the use of their personal caring qualities (Ericsson, Kjellstrom & Hellstrom, 2011: p.72).

A study by Crowther, Wilson, Horton and Lloyd-Williams (2013) found examples of both compassionate care and its opposite from interviews with bereaved family carers of people with dementia. The authors speculated that compassion fatigue among professional carers may be one explanation for the lack of compassion that some families experienced.

A significant manifestation of carers’ approach to people with dementia is how they communicate with those in their care. Perry, Galloway, Bottorff and Nixon (2005) analysed communication between nurses and people with dementia during a series of socialisation groups, generating a taxonomy of conversational strategies employed by nurses, including clarifying, exploring, moderating, validating, rescuing, connecting and assisting. The authors concluded that a rich array of conversational strategies was possible, with interactions derived from person-centred approaches to helping being particularly useful.

Studies have investigated the relationship between professional carers’ approach to people with dementia and behaviour that challenges, finding a relationship between rates of such behaviour and carers’ interpersonal skills and personality traits. Gates, Fitzwalter and Succop (2003) surveyed nursing assistants to explore the relationship between personal factors and their experience of assault by residents. They reported that respondents who had high levels of anger as a trait were more likely to have been assaulted. Skovdahl, Kihlgren and Kihlgren (2003) also interviewed carers in nursing homes, comparing homes with high and low aggressive behaviour among residents. They found that residents who felt

appreciated and respected were less likely to behave aggressively, while carers who strived to understand the meaning behind residents' behaviour and used appropriate caregiving skills, were better at ameliorating aggressive behaviour than those who acted in a custodial role.

In considering another aspect of approach, Gotell, Brown and Ekman (2000) used ethnographic methods to investigate the approach of carers during music events. They found that successful involvement by staff occurred when they expressed more of their warm side and created an emotional bond with residents, while also taking more risks and being unafraid to make fools of themselves.

2.4 Summary of Messages from the Literature

It is clear from the literature that empathy, positive attitudes and a compassionate approach are key components of person-centred care for people with dementia. Studies have found a relationship between these constructs and some evidence that, individually or collectively, they may contribute to better outcomes for people with dementia. There is not, however, a perfect fit between the constructs. Empathic understanding does not necessarily improve attitudes (Astrom et al, 1990) and positive attitudes do not always translate into a compassionate approach to care (Gotell et al., 2000). At the same time, there is enough evidence of the value of each of these constructs to warrant further investigation of the links between them by exploring the value of an 'empathy-attitude-action' framework in the context of dementia care.

SECTION 3

A REFLEXIVE ACCOUNT OF THE DEVELOPMENT OF MY MODEL OF CARING QUALITIES

Researchers, particularly those working within the qualitative research tradition, are urged to use reflexive accounting as a means of strengthening the credibility of their findings and conclusions. Reflexivity has been defined as:

“The continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence and those of the participants, which can affect the interpretation of responses” (Parahoo, 2006).

In this Section I will provide a reflexive account of the development of my model of caring, to identify the values, assumptions and experiences that shaped the studies that have formed the basis of the model and the subsequent synthesis of the findings from those studies.

After graduating in psychology, I first worked with people with dementia in the early 1980s as a nursing assistant on a ‘psychogeriatric’³ ward in a large psychiatric hospital. These were the days of minimal warehousing (Evers, 1981) of people with more advanced dementia. Personalised care was rare and the ward sister (actually a very caring person) referred without qualm to the most disabled patients as “the babies”. I am not proud of much of what I did on that ward, but even then I was convinced of the need for social and psychological care to be part of my responsibilities. I spent many hours carrying out simple activities with patients, despite my colleagues sometimes looking askance at me.

The next fifteen years of my career as a practitioner and teacher were then spent in the speciality of nursing care for people of working age with mental health difficulties. I pursued interests in person-centred counselling (PCC) and group therapy (Rogers, 2003; Egan,

³ A term accepted at the time.

2013) and also felt the growing influence of cognitive-behaviour therapy (CBT) (Beck, 1991). Having learnt about psychoanalysis during my degree course, I was unconvinced by it. I preferred the (as I saw it) more down-to-earth principles of the PCC and CBT approaches.

These were the influences on me when I returned to dementia care in the mid-1990s. It was an exciting time to do so. The revolution in thinking and practice in dementia care initiated by Tom Kitwood (Kitwood, 1997) and his followers was in full swing. Kitwood sought to relate Carl Rogers's person-centred philosophy to the care of people with dementia (Adams, 1996) and his espousal of social and psychological care principles was leading to a plethora of new approaches to care. I was keen to try out some of these new ideas but I noted that, as was the case fifteen years previously, many other nurses did not share my enthusiasm.

Encouraging both student and qualified nurses to prioritise psychological care and activities when caring for people with dementia was difficult. I published a paper reflecting on this (Pulsford, 1997), concluding that it was nurses' own values and attitudes that were the main factors in whether or not they embraced activities and other aspects of person-centred care.

I was a full time lecturer by then, but I linked with a local day hospital for people with dementia to undertake clinical work. The sister in charge was also greatly influenced by Kitwood's thinking and was experimenting with new therapeutic approaches, in particular the use of a Multi-Sensory Environment (MSE) (Pinkney & Barker, 1994). I combined my interests in therapeutic activities for people with dementia with my experience in group therapy and worked with the sister to develop 'Woodlands Therapy' (WT), a group activity approach within a MSE. It was a short step to undertaking a research project to investigate WT and its potential value (Pulsford et al., 1999; 2000).

WT included technology-based multi-sensory stimulation with play-based activities (simple ball and balloon games, dolls and soft toys). Although such activities were at the time being espoused in the literature (Perrin, 1997a; Moore, 2001), their use was controversial. Some

practitioners valued them while others felt they were demeaning to people with dementia - and to themselves (Johnson, 1998). I was interested both in promoting play-based activities and also in seeking to explain my clear observation that many people with advanced dementia manifestly enjoyed such activities.

In seeking an explanation for why people with dementia related to play-based activities, dolls and soft toys, I was influenced by my own beliefs and attitudes. In particular, I wanted to avoid psychodynamic explanations such as attachment theory (discussed in Section 4.1), due to my antipathy to psychoanalytic principles. I also did not want to embrace non-politically-correct notions such as 'returning to childhood'. In keeping with my preference for person-centred or cognitive-behavioural principles, I came to the notion of 'cognitive security' as an explanatory concept (Pulsford et al., 2000: p.656), thereby bypassing concepts (such as attachment) that I found awkward. I went so far as to suggest that participants in WT were not 'playing' at all, so keen was I to avoid accusations of childishness.

In studying WT I also began to explore the qualities needed by carers to engage in positive therapeutic activities. As I was one of the main instigators of WT, I was therefore studying myself. While I took steps to look at myself objectively (Pulsford et al., 2000: p.652), I nevertheless was motivated to regard my approach in a positive light and it was unsurprising that I regarded approvingly qualities that I personally valued, such as empathising with the perspective of participants and embracing an outgoing, uninhibited approach to participation. I thus began to create my model of caring qualities in my own image.

That image was also shaped by my preferred psychological paradigms. In promoting the value of empathy, I particularly meant the cognitive rather than the affective aspects of

empathy (Batson, 2009). Indeed, I used the term 'cognitive empathy' (inaccurately)⁴ in my published work (Pulsford et al., 2000: p.656). The notion that a key task of carers of people with dementia is to attempt to see the world as they experience it through their cognitive difficulties became a central aspect of my thinking about dementia care and was emphasised in my teaching. When I came to co-author a book for family members and friends of people with dementia, this concept, now called 'dementia empathy', became a central theme (Pulsford & Thompson, 2013).

Later, I returned to the investigation of professional carers' values and attitudes as mediators of their care decisions. Specifically, I was interested in the attitudes of staff working in care homes regarding aggressive behaviour by residents and whether their attitudes were related to the care strategies they used. I expected to find both positive and negative attitudes. In the event, respondents' attitudes were largely positive and there was evidence that those positive attitudes were linked with person-centred care approaches with aggressive residents, which was pleasing. The study used a pluralistic design, including both quantitative and qualitative methods. I was able to use some of the quantitative research skills learnt on my psychology degree to devise a survey tool to measure attitudes towards aggressive behaviour (Pulsford et al., 2011). Even this exercise, however, was influenced by my own beliefs. For example, I was thrilled to find that factor analysis of my MAPDAQ instrument produced two factors that seemed to me to reflect a person-centred versus a standard paradigm outlook and I was eager to convince my colleagues to adopt those terms as titles for the factors. Qualitative data from the study was acquired from interviews with care staff and focus groups with relatives of residents. I was struck by the highly 'person-centred' qualities of some interviewees (in the sense that their own manner and actions matched my ideal of what person-centred care should look like). Other evidence indicated

⁴ I did not discover until much later that the term 'cognitive empathy' has a more specific meaning in empathy research (Batson, 2009; Baron-Cohen, 2012)

that the person-centred respondents did actually practice in that way and my encounters with them greatly influenced my thinking regarding my construct of a 'compassionate approach'. This term was given to one of the themes derived from the analysis by my colleagues and myself of the qualitative data from this study (Duxbury et al., 2013) and I readily adopted it as a central component of my model.

The elements of my model of caring qualities were therefore present in my published work and were linked to my own outlook on dementia care and the work I carried out myself with people with dementia. They were also themes within my teaching and my book for family carers (Pulsford & Thompson, 2013).

The actual development of the model was, inevitably, an iterative process. Early iterations reflected my obsession with empathy as the central requirement of a carer. I pursued to destruction my concept of 'dementia empathy' and toyed with a construct that I called 'empathic caring', reflecting a supposed link between a carer's empathic insights and their devising an individualised response to the person's care needs. However, a difficulty arose with this model. I observed that sometimes carers demonstrated good empathic understanding of the person but appeared reluctant to make an empathic caring response to those needs. Something was missing from the model – it needed a bridge from empathy to empathic caring. It took a eureka moment to realise that the link was present in abundance in my published work: the attitudes of carers and whether these were positive or negative. Positive attitudes motivated carers to respond appropriately to the person's needs, whilst negative attitudes did not.

This insight led me to explore general research literature on the links between empathy and attitudes. I quickly came across the paper by Batson and colleagues (Batson et al., 2002) discussed in Section 1 and the simple Empathy – Attitudes – Action framework set out in his work. More pertinent still was a series of papers by Petra Gelhaus (Gelhaus 2012a, 2012b,

2013). She proposed a more refined version of an empathy-attitude-action model as an ethical framework for how doctors and other health professionals should approach their professional encounters with patients. Her use of terminology was different to mine and my model aimed to be descriptive of the good care reported in my published work rather than an ideal derived from a philosophical analysis. Nevertheless, Gelhaus's pragmatic approach chimed with my own preference for down-to-earth principles derived from the person-centred and cognitive-behavioural traditions.

My model therefore became an attempt to apply an Empathy-Attitude-Action formula to dementia care. Further iterations dropped the rather harsh term 'dementia empathy' (I am a little embarrassed that it still underpins my book for families and friends). The concept of person-centred attitudes came directly from the factor analysis of the MAPDAQ questionnaire and my ability to convince my colleagues of its validity. The term 'compassionate approach' also derived from my study of care staff's responses to aggressive behaviour and ultimately from those interviewees whose personal qualities had so impressed me. Finally, reflecting on the messages within my published work led me to revive my concept of cognitive security as the ultimate goal of care for people with dementia.

SECTION 4 – A MODEL OF THE QUALITIES REQUIRED BY CARERS OF PEOPLE WITH DEMENTIA

In this Section I describe a three-component model of the qualities required by carers in order to care successfully for people with dementia. This model has been derived from my published work and supported by related literature. At the heart of the model is a concept that I call 'Cognitive Security'. I hold that the overall aim of care is to maintain or enhance the person's sense of cognitive security. In order to achieve this, carers require the qualities of empathy with the person, person-centred attitudes and a compassionate approach to the person and to the delivery of care. I will address these concepts in turn, justifying my proposals from my published work and other literature.

4.1 Cognitive Security

Central to my model is the concept of cognitive security (Figure 2). This concept appears in the published work derived from my investigation of WT (Pulsford et al., 1999; 2000). Over time the concept of cognitive security has assumed greater prominence in my thinking and I now regard its maintenance and enhancement as the fundamental aim of care for people with dementia. Carers require the ability to judge where, in a given situation, the person with dementia's experience lies on a spectrum between cognitive security and cognitive insecurity. I define cognitive security as:

The subjective feeling of a person with dementia that (s)he perceives meaning in his/her experience and can respond to that experience to meet his/her immediate needs.

If the person does not perceive such meaning, (s)he will be in a state of cognitive insecurity.

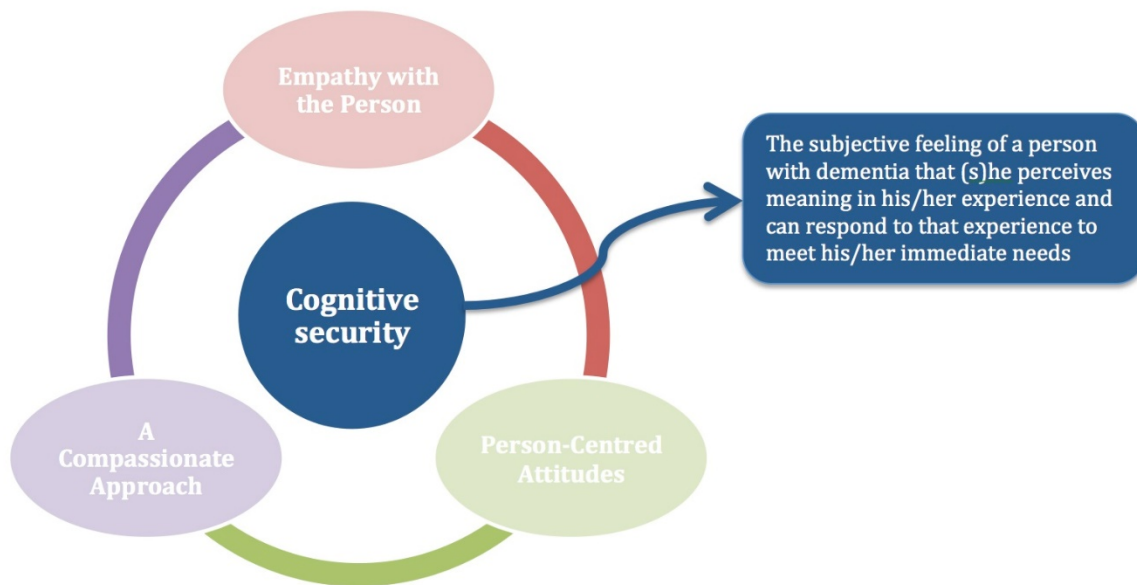


Figure 2: Three-component model with definition of cognitive security

It is important to emphasise that cognitive security is a subjective feeling and the meaning that the person perceives in his/her situation may not correspond to ‘reality’ as experienced by others. The memory, attention and executive function difficulties that progressively affect people with dementia may lead the person to misinterpret stimuli and may simplify his/her understanding of the world. This may lead to a view of the world that others find hard to understand (Perrin, 1997a). I hold that a need for cognitive security is fundamental to all people with dementia⁵ and if individuals cannot find meaning in their experience, they will experience cognitive insecurity.

It is also my view that cognitive security is closely related to well-being. For people with dementia, the world can be a confusing place and it can be hard for them to get their needs

⁵ And or those without dementia – to take a simple example, imagine that you are hiking in unfamiliar countryside and have lost your way. You are likely to experience a measure of tension and anxiety – cognitive insecurity. You then recognise a landmark that re-orientates you and you feel a surge of relief, reflecting an enhanced sense of cognitive security.

met. They may be hyper-sensitive to negative interactions with others or to the routine difficulties inherent in everyday life. Such issues create ill-being in all of us, but those without dementia can use their mental abilities to compensate and restore a sense of well-being. People with dementia, particularly as the condition progresses, may lack such abilities and require sensitive assistance from carers to regain cognitive security and thereby enhance their well-being.

In my study of WT, cognitive security was proposed as an explanatory concept for the apparent success of using play-based activities such as dolls, soft toys and children's games. I held that these activities were:

“characterised by bright, clear images and colours and simple, readily recalled actions. They are therefore understandable, at some level” (Pulsford et al., 2000: p.656).

Due to the fact that participants could understand, relate to and respond to play-based actions, I proposed that they experienced cognitive security, through:

“taking part in an agreeable activity that they can comprehend and succeed at. By doing so, they may be experiencing enhanced well-being” (Pulsford et al., 2000: p.656).

By contrast, cognitive insecurity may lead a person with dementia to exhibit “behaviour that challenges” (James, 2011). Progressive language impairment may make it difficult for a person with dementia to clearly express feelings of cognitive insecurity and the feeling may be manifested in the person's manner and actions (Rundqvist & Severinsson, 1999; Hughes, 2013). In extreme cases, aggressive behaviour may result. My study of aggressive behaviour in care homes found that care staff recognised that aggression could be the result

of residents' misinterpreting the actions of staff and feeling that their needs were not being met (Duxbury et al., 2013). Cognitive insecurity often manifested itself as an expression of frustration when the person was unable to understand why staff were not allowing them to meet their perceived needs or as a defensive reaction when residents misinterpreted the attempts of staff to assist with personal care. As one of the nurses interviewed for this study explained:

"I think a lot of it is frustration, whether it's they're frustrated because they don't understand what's going on around them or they're frustrated because they can't explain how they're feeling" (Duxbury et al., 2013: p.796).

In other cases, the manner and actions of a person with dementia experiencing cognitive insecurity might be labelled as 'confusion' or 'agitation', which may manifest in a range of maladaptive or distressed behaviours, including repeated questions, restlessness, excessive walking about and calling out. Sometimes asocial acts such as undressing, taking others' possessions or shouting and swearing may result. Dewing (2010) observes that "when agitation develops, it is most often experienced by others as unwanted or inappropriate behaviour" (p.21).

The concept of security has appeared in the dementia care literature, frequently related to Attachment Theory (Bowlby, 1969). Attachment theory talks of secure and insecure attachment styles (Hazan & Shaver, 1987). The manner and behaviour of people with dementia have been linked to the person's previous attachment style and to attachment issues in the present, particularly related to the pre-occupation with their parents that some people with dementia demonstrate (Browne & Shlosberg, 2006; Nelis, Clare & Whitaker, 2014). Attachment has been proposed as an explanation for the benefits for well-being derived from dolls and other soft toys (Bisiani & Angus, 2012).

There is evidence that the nature of attachment in childhood influences emotional and social well-being in later life (Hazan & Shaver, 1987) and it seems possible that such influences may also be present in people with dementia. However, I suggest that the need that people with dementia have for security is at a cognitive as much as (or more than) an emotional level. A fundamental understanding of the world around them (at some level) is a prerequisite for security in the sense of attachment styles.

Empathy is needed by carers to move beyond labels such as aggression, agitation and confusion and to appreciate the person's actual experience and its consequences for meeting his/her need for a sense of cognitive security. As I concluded in my discussion of the value of play-based activities in one of my papers, people with dementia:

“gain well being from being able to respond in a positive way to comprehensible experiences presented by sensitive and empathic facilitators” (Pulsford et al., 1999: p.16).

Empathy with the person therefore becomes the first key quality of a carer.

4.2 Empathy with the Person

As stated above, carers must use their empathic understanding of the person to judge, in a given situation, the person's current state of cognitive security or insecurity. In the context of dementia care, empathy has been defined as:

“having an understanding of what another person may be experiencing, getting some glimpse of what life might be like from within their frame of reference” (Kitwood, 1997: p.128).

Empathy is held to be essential for understanding the subjective experience of a person with dementia and to use that understanding to meet the person’s care needs (Stokes, 2000; Brooker, 2004). As discussed in Section 2, little research has been carried out into the empathic qualities of either professional carers or family carers. It is also the case that little work has been done to ascertain what it means to empathise with a person with dementia, whose experience of the world is likely to be very different from the carer’s experience. Based on an analysis of insights from my published work, I propose that empathy with a person with dementia embraces a number of aspects, set out in Figure 3. These come under the broad headings of Interpersonal Sensitivity; Self-awareness and Knowledge.

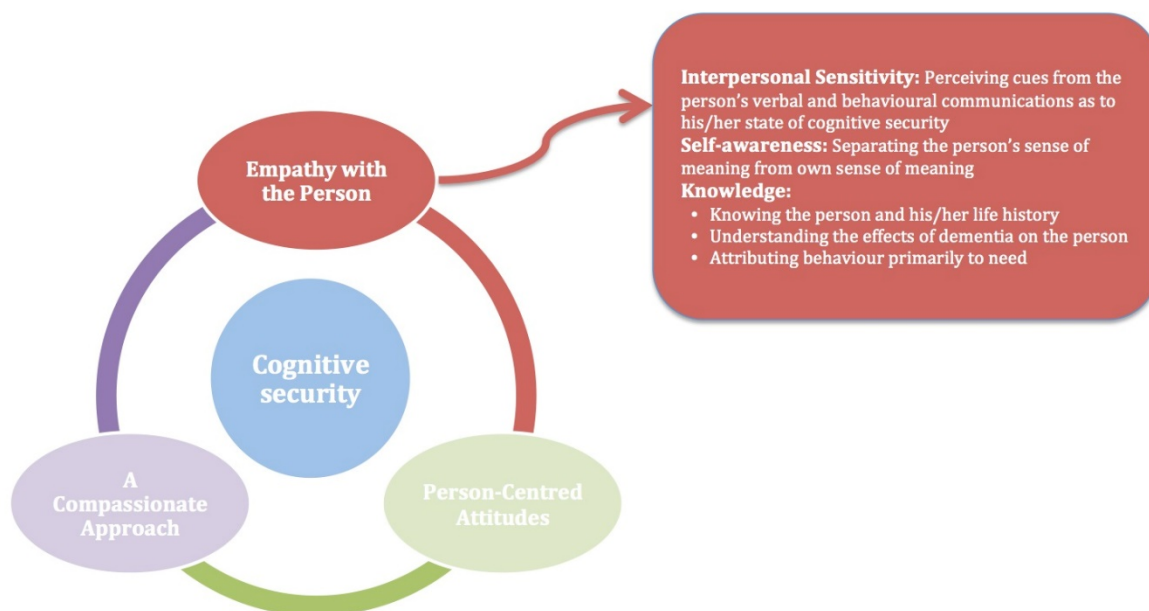


Figure 3: Three-component model with detail of empathy with the person

4.2.1 Interpersonal Sensitivity: Perceiving cues from the person’s verbal and behavioural communications as to his/her state of cognitive security

Interpersonal sensitivity refers to the ability of carers to interpret the verbal and behavioural communications of people with dementia in their care, when those people are unable to express their perspective clearly and to use those interpretations to form a theory regarding the person's state of cognitive security. Interpersonal sensitivity embraces moving beyond global labels such as 'confusion' and 'agitation' (Dewing, 2010) to appreciate the person's reactions to their situation as attempts to enhance their feelings of security. Carers must also attempt to empathise with those with more advanced dementia, who may have lost the use of language and may express their selfhood in an embodied fashion (Kontos 2005). Hughes (2013: p.356) holds that sensitive carers of people with dementia can "feel their meaning, even when it cannot be spoken". In my study of WT, an analysis of videotapes of sessions showed that the staff facilitating those sessions showed awareness of participants' reactions to the various components of WT, including when participants expressed their feelings indirectly, for example, when a participant showed her dislike of games of catch by throwing the ball into a corner of the room (Pulsford et al., 2000: p.652). As mentioned earlier, carers interviewed for my study of aggressive behaviour in care homes were sensitive to the feelings of frustration behind residents' aggressive acts. Family members who participated in focus groups shared the view that aggression was an expression of underlying frustration:

"He did it because it was frustration really...trying to tell me something, course I didn't understand what it was and then used to get really angry because I didn't understand what he was saying" (Duxbury et al., 2013: p.796).

Carers also sensed residents' feelings of threat or embarrassment during episodes of personal care, as one care assistant explained:

"He just doesn't like us messing, you know, it is like an invasion of privacy isn't it? I would probably be the same if someone came and pulled my pants down and started cleaning my backside" (Duxbury et al., 2013: p.797).

4.2.2 Self-Awareness: Separating the person's sense of meaning from own sense of meaning

As stated previously, a person with dementia achieves cognitive security if they find meaning in their experience, but that meaning may not reflect other peoples' understanding of their situation. In order to empathise with the person, carers must accordingly have the self-awareness to identify and put aside their own perspective on the person's situation in order to attempt to view that situation from the person's internal frame of reference. A key task for staff facilitating play-based activities with people with dementia was to overcome their own sense that such activities were childish and demeaning to older people and to appreciate that the participants regarded such activities in a different way (Pulsford et al., 1999; 2000). A student nurse, interviewed as part of the study⁶, commented:

“The toys and things, I just think if it makes them smile and that...if it's making them happy, I didn't agree at all that it was patronising...maybe it would be to some people...but anything that can make them smile must only be doing good, you'd imagine”.

Similarly, care home staff and family carers needed to overcome their sense that aggressive residents were being deliberately difficult, in order to appreciate the meaning of aggressive behaviour for the resident (Duxbury et al., 2013). A relative of a resident who took part in a focus group recognised her own previous inability to achieve this:

“We used to have horrendous arguments because I would say something...like ‘You've already asked me that’ and she was ‘No I haven't’ and she would really lose it. And I've had plates thrown at me...[Later] I just felt so guilty about it ..., but you

⁶ Not included in the published work for reasons of space

know you were reacting as if someone was talking to you in a rational way, now I realise that she wasn't. She genuinely didn't know" (Duxbury et al., 2013: p.797).

4.2.3 Knowledge

I further propose that empathy will be enhanced if the carer has appropriate underpinning knowledge. Understanding is required in three broad areas: knowing the person and his/her life history, understanding the effects of dementia on the person and how the carer attributes the person's behaviour.

4.2.3.1 Knowing the person and his/her life history

It is my view that a proper acquaintanceship with the person, both in terms of his/her current situation and his/her overall biography, will assist carers to contextualise the person's experience and the factors that will enhance or reduce his/her sense of cognitive security. Knowledge of individual differences in culture, interests and background helped staff personalise activities within WT sessions (Pulsford et al., 2000). This personalisation included offering participants their favoured dolls and toys and including activities that they were known to enjoy, such as listening to particular music. Understanding individual and biographical factors assisted carers to appreciate the roots of aggressive behaviour. One of the relatives explained:

"She's never been a particularly sociable person really, she likes her own space and she's suddenly been thrown into a place where I think she thinks everybody in there is somehow invading her space and she doesn't like it" (Duxbury et al., 2013: p.797).

My work in this respect has resonance with Kitwood's (1997) observation that the manner and actions of people with dementia sometimes reflects aspects of their past life and knowledge of the person's biography may help carers appreciate when the person's frame of reference may be situated in past experiences. The value of 'life story work', for example, to assist acquaintanceship and thereby empathy with people with dementia is well established (Egan et al. 2007; McKeown et al., 2010).

4.2.3.2 Understanding the effects of dementia on the person

Understanding the effects of dementia on individuals will help carers interpret their manner, actions and communications in terms of the cognitive difficulties they are experiencing. In my study of WT, staff needed to judge the extent of participants' cognitive difficulties, which were considerable, in order to make their approach understandable. I identified categories of verbal interventions that staff used during sessions and noted that some categories did not seem to be helpful as they 'outpaced' participants, for example:

"Patients were rarely able to answer memory-based questions and did not understand the staff's jokes or clever comments" (Pulsford et al., 2000: p.654).

Staff also had to adapt activities to ensure that they were understandable to participants. One example (discussed further below) was their recognition that playing with balloons was an easier activity for participants than games of catch with a ball.

Staff in my study of aggressive behaviour in care homes recognised that the cognitive difficulties of dementia were mediating factors in residents' aggressive responses to frustrating or threatening situations. The disinhibiting effects of impaired judgement lead

residents to respond with aggression in certain situations, when previously they would not have reacted in such a way. As a care assistant put it:

“They might go over the top with their aggression whereas I think if they didn’t have dementia they wouldn’t” (Duxbury et al., 2013: p.797).

4.2.3.3 Attributing behaviour primarily to need

People with dementia frequently behave in ways that others find challenging and an important facet of empathic understanding is how carers attribute such behaviour (James, 2011). Empathic carers will recognise that behaviour most commonly has meaning for the person and will attempt to sense that meaning. Interviews with care home staff from my study of aggressive behaviour suggested that they recognised that much aggression reflected what Stokes (2000) described as “poorly communicated need”, as evidenced by a comment from a care assistant:

“I just think that they get aggressive as a natural... anybody would if they are being stopped to do something, I’m preventing that lady or man to go out and get their children then I think that what’s probably kicking the aggression off” (Duxbury et al., 2013: p.797).

4.2.4 Empathy with the Person: Summary

I hold that empathy with a person with dementia is unlike empathy with someone who does not have dementia. Gaining empathic understanding of the ‘frame of reference’ of a person who has dementia involves sophisticated mental processes on the part of the carer because, as dementia progresses, a person’s experience of the world is likely to become very different to that of cognitively intact people. Also, the person may find it increasingly difficult to

communicate that experience directly (Hughes, 2013). Eritz and Hadjistavropoulos (2011) did not find a relationship between a global measure of empathy and carers' ability to be sensitive to their relatives' experience of pain. Carers (professional and family) must possess a high degree of interpersonal sensitivity to pick up and interpret verbal and behaviour cues as to the person's state of cognitive (in)security. They must have the self-awareness to recognise and put aside their own interpretations of the person's situation in order to appreciate the way the person views their situation. Empathy with the person will be enhanced by underpinning knowledge of the person and of the effects that dementia may have on an individual's particular understanding of their world. Finally, carers should attribute the person's behaviour to attempts to relieve his/her feelings of cognitive insecurity. These are demanding criteria to expect carers to achieve, but empathy with the person forms the basis of a compassionate approach to care. As such, an approach implies gearing interpersonal and caring strategies towards individual needs, which can only be ascertained through empathy.

Facets of a compassionate approach to care will be discussed later in this Section, but first I will consider the role of person-centred attitudes in mediating carers' empathic understanding and their adoption of a compassionate approach to meeting a person's needs.

4.3 Person-centred Attitudes

“Few areas of nursing care are as subject to the values, beliefs and attitudes of individual nurses as is the area of working with elderly people with dementia”
(Pulsford, 1997: p.704).

Person-centred attitudes are crucial for quality care of people with dementia (MacDonald & Woods, 2005; Sanders & Swails, 2009; Stockwell-Smith et al., 2011; Zimmerman et al., 2005). Carers need such attitudes to help them gain empathic understanding of the people for whom they are caring and to motivate them to translate that understanding into care approaches that enhance cognitive security and well-being. In line with my thinking, Gelhaus (2012b) suggests that empathy combined with a positive attitude leads to a much warmer approach to a person in need than each of those elements alone.

The importance of carers' values, attitudes and beliefs has been recognised and explored throughout my published work. In my early review of nurses' involvement in therapeutic activities (Pulsford, 1997), I suggested that such involvement was a function of their responses to three attitude-related questions: how do we regard people with dementia, who are we most concerned to help and what are our goals of care? My overall conclusion was that carers' values and attitudes were the key factor in whether or not they included facilitating activities as an integral part of their role and I reflected:

“At the end of the day, we come back to values. Do we or do we not value providing therapeutic activities for people with dementia?” (Pulsford,1997: p.708).

In my later review of professional carers' responses to aggressive behaviour by residents (Pulsford & Duxbury, 2006), I identified a number of conceptual approaches to aggression management, noting that:

“they [conceptual approaches] tend to derive from different philosophical bases, leading to the question of which approach should be preferred in any situation” (Pulsford & Duxbury, 2006: p.613).

Thus, the role of carers' attitudes in determining which approach they adopted was highlighted. I questioned whether carers were motivated to seek to understand the causes of residents' aggressive behaviour and to devise individualised person-centred responses, or whether they were simply concerned with eliminating unwanted behaviour with psychotropic drugs or physical restraints? I observed that a lack of research evidence meant that this question was hard to answer in a United Kingdom context and concluded that:

“[n]urses should consider the full range of strategies open to them for reducing incidences of aggressive behaviour, but the question remains of which approach should be tried first” (Pulsford & Duxbury, 2006: p.616).

This decision, I implied, depended on the values and attitudes of nurses and other professional carers.

Carers' attitudes were considered implicitly in my study of WT and explicitly in my study of aggressive behaviour in care homes (Pulsford et al., 2011; Duxbury et al., 2013). Analysis of the findings from these studies (and the related review papers) has led me to propose a central role for 'person-centred attitudes' in determining the extent that carers gain empathic understanding of those in their care and use that understanding to implement a compassionate approach to meeting their needs for cognitive security (Figure 4).

'Person-centred' attitudes may be contrasted with 'standard paradigm' attitudes. These terms derive from the ideas of Tom Kitwood (Kitwood, 1997: p.35) outlined in Section 1. My adoption of these terms results from my development of a rating scale to measure attitudes of professional carers regarding the causes of and best ways to respond to aggressive behaviour by people with dementia. Psychometric testing of the MAPDAQ, described in Pulsford et al., 2011) revealed two factors that, following discussion with an expert group,

were determined to represent a ‘person-centred’ perspective on aggressive behaviour in contrast to a ‘standard paradigm’ perspective. I hold that person-centred attitudes are necessary for carers, not just to promote successful aggression management, but for all aspects of care. I further suggest that attitudes held by carers include three facets: attitudes towards dementia; attitudes towards people with dementia and attitudes towards their role as carers (Figure 4). Each facet may be regarded as embracing a dimension between person-centred and standard-paradigm extremes. I will explore and justify these ideas below.

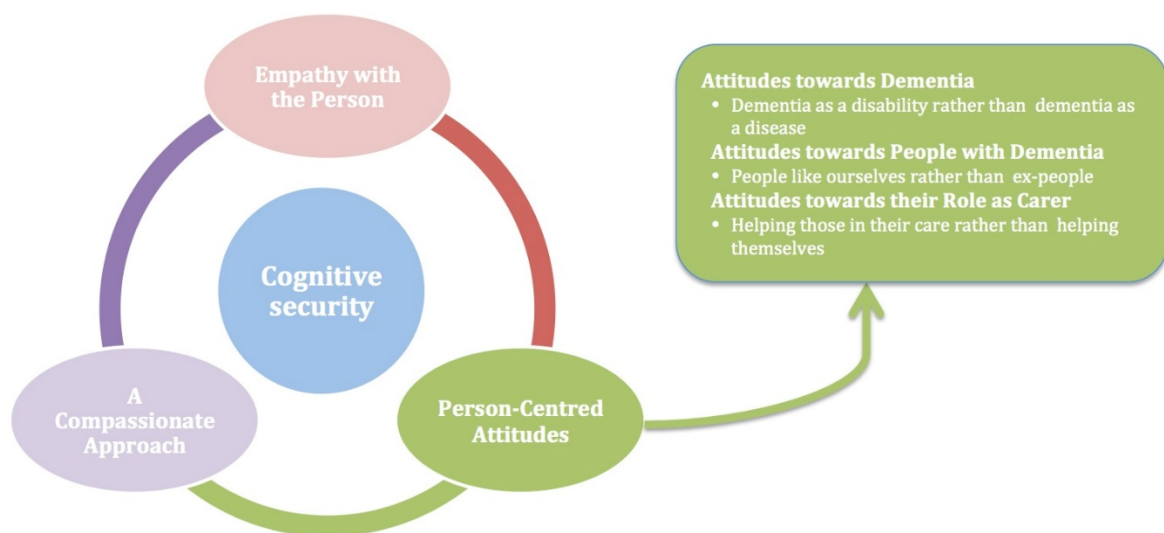


Figure 4: Three-component model with detail of person-centred attitudes

4.3.1 Attitudes towards Dementia: Dementia as a disability rather than dementia as a disease

The first attitude dimension relates to carers’ beliefs about the nature of dementia. A ‘standard paradigm’ perspective would regard dementia as being simply the manifestation of neurological disease, with the implication that the person’s behaviour was random and meaningless and should be controlled rather than understood (Kitwood, 1997: p.35). A

person-centred perspective would regard dementia as being multi-faceted, with psychological, social and biographical factors being as important as neurological factors⁷. Taking a 'disability' perspective of dementia (Gilliard, Means, Beattie & Daker-White, 2005) would imply that carers should make the effort to understand the person and their behaviour and regard psychological and social care as important as medical or physical care.

The attitudes that carers hold about the nature of dementia were investigated in my study of professional carers' attitudes towards aggressive behaviour in care homes. The MAPDAQ questionnaire (Pulsford et al., 2011) sought respondents' views regarding the causes of aggressive behaviour and the best ways of responding to such behaviour. Drawing on work by Duxbury (2003), the MAPDAQ offered respondents three broad causative factors: internal factors within the person, such as the disease process itself; external factors in the physical or social environment; or factors in the aggressive person's immediate situation or interactions with others. Questions related to internal causative factors were associated with the standard paradigm perspective on dementia while questions related to environmental or situational/interactional causative factors were associated with the person-centred perspective. In my study, respondents were most likely to view aggressive behaviour as being caused by external or situational/interactional factors, thus supporting the person-centred perspective. As mentioned previously, dementia was often seen as a mediating rather than a causative factor. At the same time, some aggressive behaviour was regarded as directly resulting from the person having dementia, as a unit manager remarked:

"I said [to a resident] when you are really really wound up at the top of your thing, is there anything, is there anything you can think of that would bring you, or help staff to

⁷ Summarised by Kitwood (1997) as Dementia = Neurological Impairment + Personality + Biography + Health + Social Psychology.

calm you down and he went 'fraid not, it's now the way I am'" (Duxbury et al., 2013: p.797).

The MAPDAQ also asked for respondents' views regarding the best ways of responding to aggressive behaviour, within the broad categories of non-physical approaches, medication, isolation and restraint. Factor analysis associated non-physical approaches with the person-centred perspective and the other approaches with the standard paradigm perspective. Staff in my study strongly supported non-physical means of responding to aggressive behaviour and my subsequent audit of aggressive incidents showed that they predominantly employed non-physical strategies (Pulsford et al., 2011). Overall, my development and use of the MAPDAQ has demonstrated that it is possible to identify and measure person-centred versus standard paradigm attitudes towards dementia, at least those related to carers' beliefs regarding aggressive behaviour.

4.3.2 Attitudes towards People with Dementia: People like Ourselves rather than Ex-People

One factor influencing attitudes towards people with dementia will be individual's beliefs regarding the nature of dementia itself. In my early review and discussion paper on therapeutic activities (Pulsford, 1997: p.704), I regarded attitudes towards people with dementia as a dimension between regarding people with dementia as people like ourselves (reflecting a person-centred perspective) or as ex-people (reflecting a standard paradigm perspective). These contrasting views may be related to Buber's (1937) concepts of 'I – Thou' and 'I – It' relationships (cited by Kitwood, 1997: p.10). In my paper I discussed the practical and ethical implications of professional and family carers holding either of these views. In general, carers who regard people with dementia as people like ourselves are likely to be more motivated to regard psychological and social care, including therapeutic

activities, as being important for the person, while an attitude of regarding them as ex-people will at best be associated with a task-orientated approach that prioritises physical care and at worst, neglect and abuse (Pulsford, 1997: p.705)⁸.

4.3.3 Attitudes towards their Role as Carers: Helping those in their Care rather than Helping Themselves

The third facet of attitudes relates to what carers regard as being their priorities when in the caring role. In my review of activities, I posed the question: “who are we most concerned to help”? (Pulsford, 1997: p.705). I noted that professional carers (from a person-centred perspective) could put those in their care in the forefront and embrace the necessity for social and psychological care, or they could regard minimising the practical or emotional demands on themselves as their main priority (reflecting a standard-paradigm perspective). I commented that:

“[s]ometimes, the predominant value in a unit is for the staff to protect themselves, or to make life easier for themselves” (Pulsford, 1997: p.705).

Again, the approach of a carer who holds such attitudes is likely to be task orientated (Stockwell-Smith et al., 2011), or a carer may prioritise other service users over people with dementia (Sanders & Swails, 2009). In extreme circumstances, care may become neglectful and abusive (Eriksson & Saveman, 2002).

Related to staff responses to behaviour that challenges, such as aggressive behaviour, an attitude of “helping themselves” may lead carers to opt for physical or pharmacological

⁸ I also discussed the possibility of regarding people with dementia as “people with disabilities” (Pulsford et al., 2000: p.705)

approaches. In my review of aggression management approaches, I remark that the pharmacological approach:

“...focuses on using medication to minimise the occurrence of unwanted behaviour, rather than assisting people with dementia to interact with others, or to get their needs met in more positive ways” (Pulsford & Duxbury, 2006: p.614).

Carers may therefore regard this approach, which I relate to the standard paradigm perspective (Pulsford & Duxbury, 2006: p.613) as an ‘easier’ option than non-physical or person-centred means. However, my study of aggression management showed that staff in the relevant care homes did not in general pursue this option. A relative commented:

“I’ve been in homes where they’ve been I would say drugged up. You know they have a policy [here] that that doesn’t happen and I admire them for that because they like the person to be the person” (Duxbury et al., 2013: p.798).

4.3.4 Person-centred Attitudes: Summary

In summary, drawing on insights and findings from my published work, I propose that it is possible to identify two broad attitude perspectives that may be held by carers of people with dementia, which, following Kitwood (1997), I term the ‘person-centred’ and ‘standard paradigm’ perspectives. These manifest as attitudes towards the nature of dementia; towards people with dementia and towards priorities when undertaking the caring role.

Person-centred attitudes hold a central place in my model of caring qualities as they provide a link between carers’ manifestation of empathy with the person and their adoption of a compassionate approach to care. Research in the field of social psychology indicates that empathy with a person or group can improve an individual’s attitudes towards that group

(Batson et al., 2002). I would further suggest that a carer who holds person-centred attitudes is more likely to attempt to empathise with people with dementia in their care (MacDonald & Woods, 2005). Batson et al. (2002) also propose that positive attitudes towards people in need are linked with a stronger inclination to help those people, leading to their empathy – attitude – action model, outlined in Section 1. I would strongly argue that holding person-centred attitudes is a pre-requisite for carers of people with dementia in order for them to adopt a compassionate approach in practice (Bahareethan & Shah, 2000; Hutchinson & Marshall, 2000; Rundqvist & Severinsson, 1999; Tranvag et al., 2013). Regardless of how well a carer understands the ‘frame of reference’ of a person with dementia, if the carer does not hold person-centred attitudes, he/she will likely not care for the person in a way that has the enhancement of cognitive security and well-being at its heart.

4.4 A Compassionate Approach

“She takes everything in her stride, she does it easily, she’s very clever is Anne⁹ with all situations. She seems to have compassion ... everyone seems to love her. You know you can come in here and Anne will be sat there nice and peaceful and yet when Anne ain’t on some days you come in and there’s one or two playing up. She takes it all matter of fact; nothing seems to faze her” (Duxbury et al, 2013: p.798).

The above quote, a fulsome tribute paid to a unit manager by a relative who took part in a focus group as part of my study of aggressive behaviour in care homes, epitomises a ‘compassionate approach’. This term is also used in the related paper as a key requisite for a successful response to aggressive behaviour (Duxbury et al., 2013: p.798). A compassionate approach embraces both the skills and strategies of care delivery and the

⁹ Names of carers and people with dementia mentioned in quotes from the papers have been anonymised.

personal manner and interaction style of the carer, which I hold to be as important as the components of care¹⁰.

The term 'compassion' is today widely used in healthcare. A key recommendation of the Francis Report (Department of Health, 2013) was that service users should have the right to be looked after for by people who are caring, compassionate and committed. Much has been written about compassion and compassionate care, but there is little agreement regarding definitions of these terms. A narrative synthesis by Dewar et al. (2011) concluded that compassion primarily involves an awareness of another's feelings, an appreciation of how they are affected by their experiences and interacting with them in a meaningful way. In this reading, compassion therefore embraces both empathy and how the carer responds to those in their care. This perspective is reinforced by the Department of Health's '6Cs' formula, which defines compassion as:

“how care is given through relationships based on empathy, respect and dignity - it can also be described as intelligent kindness, and is central to how people perceive their care” (Department of Health, 2012a: p.13).

Gelhaus (2012b: p.397), on the other hand, regards compassion as a “professional attitude' that results from empathy and which motivates the carer to help others.

My term, a 'compassionate approach', is more aligned to definitions provided by Dewar et

¹⁰ It was a concept that came up frequently in interviews with care home staff. Asked for her views on the best ways to respond to aggressive behaviour, the Unit Manager who was the subject of the above quote replied simply, “Approach”.

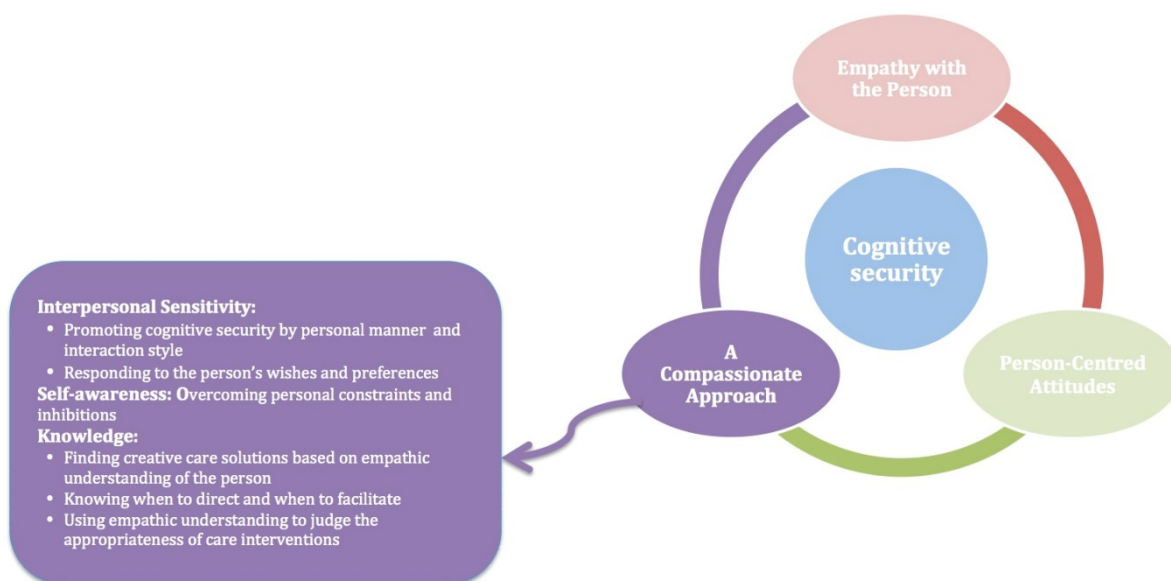


Figure 5: three-component model with detail of a compassionate approach

al., (2011) and the Department of Health (2012a) and implies that compassion requires carers to go beyond having sympathetic feelings for others by acting to help them meet their needs. It embraces not just what carers actually do to help people with dementia meet their needs, but also how they do it, making the point that the carer's personal manner and verbal and non-verbal interaction style will be as important as the actual care acts they carry out.

Like empathy, a compassionate approach requires interpersonal sensitivity, self-awareness and knowledge (Figure 5) and empathy is required by the carer to judge the best specific care strategy for an individual in his/her care. I will address these components in turn.

4.4.1 Interpersonal Sensitivity

Caring for a person with dementia should be an interpersonal process and carers need interpersonal sensitivity to successfully demonstrate a compassionate approach to care.

Interpersonal sensitivity embraces the carer's personal manner and interaction style and his/her sensitivity to the person's needs and wishes.

4.4.1.1 Promoting Cognitive Security by Personal Manner and Interaction Style

Promoting cognitive security is the crux of a compassionate approach. The carer must use empathy to assess the person's state of cognitive insecurity and adopt a personal manner and interaction style that will enhance cognitive security rather than reduce it. Both verbal and non-verbal aspects are important. The Unit Manager referred to in the previous quote epitomised a positive personal manner, but as Gates et al., (2003) and Skovdahl et al., (2003) note not all carers display this quality. Another Unit Manager in my study remarked:

“[You need to know] when to back-off a little bit from somebody who's aggressive, not argue, because I have seen people, they'll labour a point with a resident – ‘Now come on Jim, drink your soup up or drink this or drink that.’ ‘No, I don't want it.’ ‘Now come on it's good for you. Now come on, we don't want you not eating, you know what your daughter said.’ ‘I'm not hungry, I don't want it.’ ‘Well I'll have to tell your daughter,’ and it's the attitude of that particular person” (Duxbury et al., 2013: p.797).

The same Unit Manager advocated a calming personal manner as an alternative to physical restraint in aggressive situations:

“I don't feel that a lot of physical restraint has been absolutely necessary, you know, I don't feel that is the way. I think 99.9% of the case it'll be talked through or just an arm around the shoulder and brought away, you know” (Duxbury et al., 2013: p.798).

In my study of WT I identified a range of verbal communication strategies employed by staff and noted that these were differentially effective at promoting wellbeing among participants.

“Patient-centred” interventions (Pulsford et al, 2000: p.654), including reflections of things said by participants were the best manifestations of a compassionate approach, a point also noted by Perry et al. (2005). Pulsford et al. (2000: p.654) includes contrasting extracts from conversations between staff and individual participants that illustrate both an empathic and non-empathic interaction style¹¹. In summary, a calm, non-intrusive and non-threatening personal manner and a verbal interaction style that seeks to understand and respect the frame of reference of the person are most likely to engender a sense of cognitive security in people with dementia. As Perry et al. (2005: p.50) concluded:

“A supportive, engaged conversational partner enhances both the partner’s understanding as well as the person with dementia’s satisfaction at being understood”.

4.4.1.2 Responding to the Person’s Wishes & Preferences

A compassionate approach behoves staff to respond to the person’s wishes and preferences, if it is possible for them to do so. In WT sessions, this was manifested by staff getting to know individual participants’ likes and dislikes regarding the various components of the activity and responding accordingly by, for example, not insisting on participants playing games that they indicated (sometimes indirectly) that they were not fond of (Pulsford et al., 1999; 2000), or by giving participants’ their favourite doll or toy, for example:

“One lady became very attached to a battery-operated parrot which repeated back what was said to it. She asked after the parrot at the beginning of each session and talked to it at length, chuckling at the responses” (Pulsford et al., 1999: p.15).

¹¹ Not reproduced here for reasons of space.

The nurse who devised WT commented¹²:

“Sometimes it leads itself, by what they say and do and if they notice an object, say the balloons...then I’ll introduce that. I don’t think there’s any set interventions for me really, I tend to go with a gut feeling and take their lead really”.

With aggression management, responding to the person’s wishes and preferences may of course be less easy, as aggressive behaviour often resulted from staff either doing things that the person disliked (such as personal care) or preventing them from doing things that they wanted to do (such as leave the unit). In these cases, such non-empathic actions needed to be justified as being in the person’s best interests and carers recognised the diminution of cognitive security that they entailed. One relative told us:

“A few months ago she’s let her hair ... she wouldn’t have it cut ... she let it grow for about six months and it was here, and it looked awful, she wouldn’t let them wash it or touch her and it eventually got so bad that two of them held her while one cut it. We said ‘If you hold her we’re happy, you know’, it was awful, it really was awful” (Duxbury et al., 2013: p.798).

4.4.2 Self-awareness: Overcoming Personal Constraints to Creating a Positive Relationship with the Person

Compassionate caring occurs in the context of a positive relationship between the carer and the person with dementia. My view of caring relationships focuses on the fact that people with dementia find relationships harder to initiate and sustain because when memory, attention and language difficulties progress they increasingly lack the mental resources to

¹² Not included in the published work for reasons of space

interact with others. This means that carers need the self awareness to recognise that they must reach out to the person more than would be required to create a relationship with someone who did not have dementia. This is necessary to compensate for the person's communication difficulties (Pulsford & Thompson, 2013: p.107). The carer needs empathy to judge the extent and manner in which he/she must reach out to the person to attempt to achieve an 'I –Thou' relationship (Buber, 1937).

Tom Kitwood promoted the value of a less inhibited (and thereby more compassionate) approach to interacting with people with dementia. Discussing the nature of positive person work, he opined that the "quality of interaction is warmer, more rich in feeling, than that of (British) everyday life" (Kitwood, 1997: p.90). A particularly good example within my published work of a carer who had the ability to reach out to people with dementia in a compassionate way is that of an outgoing and bubbly student nurse who facilitated a WT session. She used party blowers as part of the session and the sense of fun that she brought to the activity gained a much better reaction from participants than the regular facilitators were able to evoke (Pulsford et al., 1999: p.15). In general, an uninhibited outlook was needed by the staff who took part in WT, in order to embrace the multi-sensory and play-based activities that formed the basis of the activity. I can recall my own doubts when I first encountered WT and felt that some of the more garish soft toys that the staff were using were too childlike and demeaning for participants (Pulsford et al., 1999). I needed to transcend my own natural diffidence in order to take part effectively in sessions. The nurse who devised WT remarked¹³:

"I think the fact that we do exactly the same as they do helps in that we don't sit back and watch them interacting with the soft toys or the music but that we join in and I think that makes them feel comfortable, it's as if we're one of them".

¹³ Not included in the published work for reasons of space.

The importance of such openness in relationships between carers and people with dementia has also been highlighted in the literature (Gotell et al., 2000; Nolan, 2006; Ericsson et al., 2011).

4.4.3 Knowledge

By knowledge, I mean in this context both empathic understanding of the person and broader knowledge of a range of appropriate care strategies and psycho-social interventions¹⁴. Key knowledge requirements include finding creative care solutions based on empathic understanding of the person and knowing when to direct and when to facilitate as well as using empathic understanding to judge the appropriateness of care interventions.

4.4.3.1 Finding Creative Care Solutions based on Empathic Understanding of the Person

When carers recognise that a person with dementia is experiencing cognitive insecurity, they must employ their empathic understanding of the person to find a creative care solution that will enhance cognitive security. One such example from my study of WT was the facilitators' realisation that games of catch with soft balls were too complex for some participants as they could not understand the 'rules of the game' (Pulsford et al., 2000: p.653). When a ball was thrown to them they appeared uncertain, not able to appreciate that they should catch the ball and throw it to someone else. The uncertainty that participants experienced appeared to increase their level of cognitive insecurity and reduced their sense of enjoyment of the activity. The facilitators substituted balloons for the balls and these proved more successful as participants could understand the simpler task of patting away a balloon that floated near

¹⁴ Which may include sensory-motor therapeutic activities such as WT.

to them. In this way, cognitive security was enhanced and participants gained greater well-being from the game.

Interviews and focus groups with care home staff and relatives of residents within my study of aggression in care homes also highlighted examples of creative care strategies (Duxbury et al., 2013). Interviewees showed awareness that approaches to interaction that did not acknowledge the perspectives of residents could trigger aggressive responses and offered examples of their own creative empathic caring strategies. A relative told us:

“If [my mother] is really, really getting upset I’ll say ‘Right I’m going now’ and I’ll go and sit with another resident until she’s calmed down and then come back and then it’s just as if she’s never seen you” (Duxbury et al., 2013: p.798).

Another example, related by a care assistant, that did not ‘make the cut’ for inclusion in the published paper is reproduced below:

“I have found, you know the Wurzels - ‘I’ve got a Combine Harvester’ that song. If I play that to Fred, he will start tapping his feet, so when we have to [carry out personal care], I usually put that on and he is too busy listening to that he seems to forget about [what we are doing] ... for them few minutes it does calm him and then we ... think right we can do this without him hitting us, and it is good because [otherwise] we have to restrain him and it is not nice being in a full restraint”.

It is evident that the Wurzels’ chart-topping song enhanced Fred’s sense of well-being (even though it may not enhance our own!). Analysing this vignette, it can be seen that, like many people with more advanced dementia, Fred experienced cognitive insecurity when staff attempted to carry out personal care activities that he could not undertake himself, through lack of understanding of carers’ motives and consequent feelings of threat and violation.

Playing a favourite song to Fred while carrying out such activities attracted his (limited) attention and enhanced cognitive security through its familiarity and the fact that Fred could respond to it (by tapping his foot). Fred's attention was diverted from the feeling of threat that might otherwise be induced by the carer carrying out personal care¹⁵. Overall, empathic understanding of a person's personal background and the effects of dementia on the person enables compassionate carers to adopt care creative care approaches that relieve cognitive insecurity and promote greater well-being.

4.4.3.2 Knowing when to Direct and when to Facilitate

Carers need to know when to be directive and when to be facilitative when caring for people with dementia; in other words, when to take the lead and guide the person and when to assist the person to manage things for themselves (Tranvag et al., 2013). This aspect of decision making requires empathic understanding of the person's capabilities and wishes. It also requires positive attitudes, as facilitating people with dementia to do things for themselves may be more demanding on carers' time and may require them to tolerate degrees of risk.

In my study of WT, staff attempted to strike a balance between being directive and being facilitative. A clear finding from the study was that proactive leadership was needed for WT sessions to be successful. As reported in Pulsford et al. (2000: p.653) some sessions were put on where staff took a passive role, simply playing music and showing multi-sensory images. Participants in these sessions did not interact or pay much attention, spending most

¹⁵ Some might say that the carer's strategy was motivated simply by her need to keep safe while undertaking personal care and concern for Fred's well-being was not a factor in her actions. I prefer to take a more positive view of this vignette. The carer clearly regarded Fred's well-being as being as important as her own. The value of "meaningful moments" such as this for the well-being of people with dementia has been highlighted (Hillier & Stokes, 2012).

of the session dozing; the electronic equipment on its own was not sufficient to gain their attention. However, while actively leading sessions staff endeavoured to achieve a balance between a directive and facilitative approach, encouraging participants to initiate activities or interact with each other. As the nurse who devised WT explained in an interview conducted as part of the study¹⁶,

“I suppose I see my role as being a facilitative one, helping [participants] to enjoy and interact with whatever’s on offer...[but] you have to do a little bit of leading and a little bit of instigating”.

A student nurse saw facilitation as being linked to prompting participants to engage:

“I felt you had to keep prompting the clients to play with the dog or kick the ball or whatever, they wouldn’t do it on their own...some of them would but you have to say ‘Come on, just kick it’”.

A similar balance between carers directing and facilitating was apparent in my study of aggression management. A principal theme that emerged from interviews with staff was “not going in strong”; recognising the importance of using directive, ‘controlling’ strategies sparingly and sometimes waiting to see if incidents resolved themselves (Duxbury et al, 2013: p.798). As a senior nurse explained:

“You don’t need to go in all guns blazing. To physically restrain anyone when they’re getting violent, it makes them worse. . . You’ve got to try and talk to them” (Duxbury et al, 2013: p.798).

¹⁶ Not included in the published work for reasons of space.

4.4.3.3 Using empathy to judge the appropriateness of care interventions

The final component of a compassionate approach is the need for carers to continually monitor the person's verbal and non-verbal cues to assess the success or otherwise of their attempts to enhance the person's sense of cognitive security and modify their care strategies accordingly. Empathy of course remains central to this process. At the same time, with people in the more advanced stages of dementia, gaining such feedback can be difficult, due to their limited verbal and non-verbal communication abilities (Hughes, 2013). Carers sometimes have to trust that their theories of the person's state of cognitive security are accurate and that their care strategies are meeting the goal of enhancing well-being.

4.4.4 A Compassionate Approach: Summary

A compassionate approach to caring for a person with dementia therefore requires that carers possess interpersonal sensitivity, self-awareness and knowledge of the person and of a range of care approaches. These aspects are also required for empathy with the person. Empathy is essential for a compassionate approach as it is based on the carer understanding the person's specific needs, strengths and cognitive difficulties. Interpersonal sensitivity is needed by the carer so that (s)he may enhance the person's sense of cognitive security through a positive personal manner. It is also needed to enable the carer to perceive and respond to the person's needs and wishes. The carer needs self-awareness to identify and transcend personal constraints to creating a positive relationship with the person. Carers require knowledge of a range of care strategies and when to direct and when to facilitate. Finally, carers need to use their empathic understanding of the person to judge the effectiveness of their approach and to modify that approach if necessary.

Underpinning a compassionate approach are person-centred attitudes, the possession of which will motivate carers to find and implement individualised ways of enhancing cognitive security in those in their care (Nakahira et al., 2008; Duxbury et al., 2013).

SECTION 5 – DISCUSSION

In Section 4 of this thesis, I presented a three-component model of the qualities required by carers of people with dementia and provide detail of the sub-components of each quality. This model represents a synthesis of findings and insights from my published work on aspects of dementia care. It is based on the 'empathy-attitude-action' framework proposed by Batson et al. (2002) and Gelhaus (2012a & b; 2013) and also draws on Kitwood's (1997) conceptualisation of 'person-centred' care as a contrast to 'standard paradigm' care. I believe that my model offers a credible and potentially useful account of the personal qualities, skills, attitudes and knowledge that both professional and family carers require in order to enhance cognitive security, and thereby contribute to well-being, in people with dementia. As such, I believe that this thesis, that synthesises my published work and presents a coherent discussion of the model, makes an original contribution to dementia care, with implications for practice, education, policy and research.

5.1 Implications for Dementia Care Practice

With rising numbers of people with dementia in the UK and elsewhere (Alzheimer's Disease International, 2013), the care of people with dementia is assuming greater importance. Over 60% of care home residents in the UK have dementia and a quarter of acute hospital beds are occupied by people with dementia (Alzheimer's Society, 2009). At the same time, two-thirds of people with dementia live in the community, normally with the support of a family carer (Alzheimer's Society, 2011). Quality care for people with dementia has never been so necessary.

Despite Tom Kitwood's notion of person-centred care having been proposed twenty years ago, the current care of many people with dementia frequently bears greater resemblance to 'standard paradigm' practice or worse. The Francis Report into Mid-Staffordshire NHS Foundation Trust (Department of Health, 2013) highlighted the devastating effects of a lack of compassion towards older patients who were patients of the Trust, many of whom will have had dementia and called for a "culture change" in the NHS to promote caring and compassionate values. Reports of abusive care of people with dementia in care homes appear with depressing regularity, as evidenced by the work of Milne, Cambridge, Beadle-Brown et al., (2013). Abuse and neglect of people with dementia in the community (by family as well as professional carers) has also been highlighted (Cooney, Howard & Lawlor, 2006). Even where care is not abusive, indicators such as high usage of psychotropic drugs with people with dementia (All-party Parliamentary Group on Dementia, 2008) suggests that care is frequently not based on a person centred compassionate approach but instead a medical model (standard paradigm) approach.

As well as setting out what professional carers need in order to give care that enhances well-being through promoting cognitive security, my model of caring qualities also provides clues as to why such care is apparently so hard to achieve in practice. One factor is the relative complexity of the mental processes that carers must apply in order to empathise with people with dementia and to implement a compassionate approach. These qualities require high levels of interpersonal sensitivity, and self-awareness. Added to this, carers must have underpinning knowledge of how dementia affects the individual in order to generate accurate understanding of the person's often, dynamic state of cognitive security. Finally, biographical knowledge of the person is needed for professional carers to relate their understanding of the effects of dementia to the individual. However in many care settings such information may not be available.

The relationship-forming and solution-finding requirements of a compassionate approach to care may also tax professional carers as they may find it difficult to reach out to people with dementia to the extent that is needed, even if their attitudes are positive ones (Sung et al., 2011). Also, finding appropriate care strategies often requires cognitive sophistication and creativity. Authors such as Stokes (2000) and James (2011) who discuss behaviour that challenges include many examples of imaginative approaches to individual care needs but one wonders how many care staff have this level of creativity or the scope to be as creative.

Caring for people with dementia therefore places cognitive and emotional demands on carers that they may struggle to fulfil, particularly as many care staff lack both general education and specific training in dementia care (All-party Parliamentary Group on Dementia, 2009). Astrom et al. (1990) suggested that unqualified care staff may have lower levels of empathy than qualified nurses. At the same time, it would be wrong to assume that untrained or uneducated care staff cannot demonstrate the qualities of empathy and compassion (or for that matter that educated carers are universally empathic and compassionate). Unqualified staff interviewed for my study of aggression management showed good empathic awareness and a creative approach to care (Duxbury et al., 2013). Sheard (2004) talks of unqualified staff who appear to be 'naturals' and who apparently are able to empathise with people with dementia without background knowledge, or the ability to articulate how they come by their empathic insights. A future direction for research could be to investigate such claims further, to ascertain what proportion of care staff could be regarded as being 'naturals', how those qualities may be manifested and what factors in their backgrounds might have promoted their empathic abilities.

The focus groups with relatives of residents carried out as part of my study of aggressive behaviour in care homes (Duxbury et al., 2013) showed that, like professional carers, some family carers demonstrate excellent caring qualities, being acutely aware of the person's sense of cognitive security and using creative care strategies to relieve difficult situations and enhance well-being. At the same time, it is evident that not all relatives or informal carers are equally able or willing to take the perspective of the person with dementia or they may require advice and support in the context of a therapeutic relationship with an empathic professional in order to do so (Keady, Ashcroft-Simpson, Halligan & Williams, 2007).

Person-centred attitudes are crucial. Even when carers possess empathic understanding, if they do not value the enhancement of well-being for people with dementia, they will not be motivated to seek to empathise with the person or to learn the complex cognitive and emotional skills of a compassionate approach to care. Also, my clinical and teaching experience leads me to question the suggestion by Batson et al.(2002) that empathy directly leads to positive attitudes, which in turn motivates a person to help another in need.

Sometimes a carer will show good empathic awareness of a person's state of cognitive insecurity and also show understanding of an appropriate compassionate care approach, but for a variety of reasons does not implement that approach. The carer opts instead for an easier course of action (often emanating from a standard paradigm perspective). Sometimes this is due to practical or resource constraints or something within inhibits or demotivates the carer but, as in Astrom et al.'s (1990) work, often it can be traced to being insufficiently person-centred. How to inculcate person-centred attitudes in carers is the ultimate challenge of dementia care and one that to date has only been partially and to some extent inconsistently achieved.

5.2 Implications for Education and Training

A series of reports and policy documents over the past decade have highlighted inadequacies in care for people with dementia (Department of Health, 2005; Royal College of Psychiatrists, 2006; Age Concern, 2006; Alzheimer's Society, 2007; National Audit Office, 2007; All-Party Parliamentary Group on Dementia, 2009). All have recommended enhanced education and training for professional carers. This culminated in the recommendations on workforce development contained within the National Dementia Strategy (Department of Health, 2009)¹⁷. My model of caring qualities highlights areas towards which education and training should be focused, but also indicates the challenges to improving care through education or training.

My model emphasises that both professional and family carers need knowledge and understanding in order to fulfil their caring role, beginning with appreciation of the central place of cognitive security as a main goal of care. Education in the effects of dementia on individuals and the value of seeing the person in the context of his/her life history will assist carers to empathise with those in their care. Carers may also be taught to recognise and interpret the person's behavioural cues and to appreciate that their sense of meaning may be different to the person's. Principles of cognitive-security enhancing communication may also be taught and carers introduced to strategies for finding creative care solutions in a range of situations. Many papers have been published describing and evaluating education and training initiatives that seek to address these or similar issues (recent examples include Broughton, Smith, Baker et al., 2011; Elvish, Burrow, Cawley et al., 2014; Passalacqua & Harwood, 2012; Smythe, Jenkins, Harris et al., 2014).

¹⁷ Operationalised in the Department of Health's mandate to Health Education England for developing the healthcare workforce (Department of Health, 2012b)

My study of aggressive behaviour among care home residents offers some indirect evidence for the value of education and training in promoting best practice (Pulsford et al., 2011; Duxbury et al., 2013). Care staff in this study mostly demonstrated good empathic understanding of residents' perspectives and evidence of compassionate care approaches. The company that owned the care homes in which the study took place has a strong record of education and training and leading figures in the company have a national reputation for promoting person-centred care. I speculate whether such positive findings are representative of the whole care home sector, given the non-universal provision of high-quality training in that sector (Pulsford et al., 2011: p.103).

Other research has indicated that while necessary, education and training are not sufficient to enhance practice (Lintern, Woods & Phair, 2000; Hope & Waterman, 2004). Education and training need to be part of a whole-systems approach to care improvement (Huckshorn, 2007) if long-term cultural change has a chance of occurring. As suggested earlier, inculcating person-centred attitudes among carers remains a key challenge of dementia care. Stokes (2010: p5) remarks that:

“My feeling...is that people do not learn person-centred ways of engaging with people with dementia: it is something you feel, it's something you do because your heart and mind is in the right place, it's something you get – or possibly some people don't.”

In a book for family members and friends, my co-author and I make the same point albeit in a different way:

“What we can't do is give our readers a positive attitude towards people with dementia. That has to come from within” (Pulsford & Thompson, 2013: p.42).

5.3 Implications for Policy

Policy towards the care of people with dementia in the United Kingdom has embraced the person-centred philosophy (Innes & Manthorpe, 2012). Recent policy statements, including the National Dementia Strategy (Department of Health, 2009) and the Prime Minister's Challenge on Dementia (Department of Health, 2015) espouse the principle that the maximisation of the person's quality of life should be the primary goal of care. This has to be achieved, however, in an environment in which the numbers of people with dementia are growing and the present government's austerity agenda is limiting public spending on health and social care.

Policy initiatives related to the Prime Minister's Challenge such as 'Dementia-friendly Communities' (Alzheimer's Society, 2013) and 'Dementia Friends'¹⁸ aim to raise awareness of dementia and to mobilise public support for people with dementia and their families. As such, they have echoes of the Government's 'Big Society' philosophy of communities reinforcing government as a provider of public services (Cabinet Office, 2010). The success of such initiatives will depend on the personal qualities and enthusiasm of the individuals who volunteer for them. My model of caring qualities may be applied at all levels, to include those lay volunteers and ordinary members of the public who become Dementia Friends or assist people with dementia living in 'dementia-friendly' communities. Awareness-raising training should include equipping individuals with the understanding of dementia needed for empathy with people with dementia and basic principles of a compassionate approach to helping people with dementia meet their needs. Additionally, individuals taking on such roles will need person-centred attitudes to motivate them to embrace such voluntary roles.

¹⁸ <https://www.dementiafriends.org.uk/>

The austerity agenda implies that financial resources for formal dementia care are unlikely to increase in real terms and may well be squeezed further. Added to this, the increase in numbers of people with dementia will lead to their increased prevalence in other health and social care settings, including acute hospitals (Alzheimer's Society, 2009). This naturally places the onus on nursing and other care staff to provide high-quality person-centred care in the context of limited resources. Debate has raged as to how feasible this is. Many nurses and care staff tell researchers (and teachers running continuing professional development courses) that they would like to implement person-centred care but are constrained from doing so by lack of time or material resources (Crowther et al., 2013; Innes & Manthorpe, 2013; Spencer et al., 2014). At the same time, the correlation between resources (including staffing numbers) and person-centred care is not a perfect one (Perrin, 1997b, Hope & Waterman, 2004, Lai et al., 2009). Harmer & Orrell (2008) found that care home staff cited lack of time as the main reason for not undertaking activities with care home residents, while residents and family members attributed lack of activity to staff being unmotivated. These factors resonate with the synthesis of my work presented in this thesis.

Applying my model to this debate, staff need empathic understanding of the people in their care to identify residents' needs and a range of person-centred strategies for implementing a compassionate approach to care. However, they also need person-centred attitudes and extra resources will never compensate for the absence of such attitudes. In short, enhanced resources may make person-centred care easier, but resources alone will not improve care if staff do not possess the caring qualities set out in my model.

This is not, however, to argue against better resources for dementia care. Committed, person-centred staff with good resources will surely help those in their care achieve a better quality of life than if resourcing is poor. Rhetoric, as heard from some politicians in the wake of the Francis Report (Department of Health, 2013), that the dreadful outcomes for older people at Mid-Staffordshire NHS Trust were simply the result of a lack of compassion by

nursing staff was as unhelpful as that from the nursing unions who attributed all the problems to underfunding. Governments should recognise their obligations to people with dementia and provide a level of resourcing that enables them to achieve a decent quality of life. At the same time, carers, professional, family and voluntary, should also accept the responsibilities that come with that role and embrace the personal qualities needed to fulfil it.

5.4 Directions for Future Research

A number of areas might be explored through future research to build on the ideas presented in this thesis. The model itself would benefit from being tested for validity and utility. Quantitative testing would require the development of psychometric measures of its components. A number of measures of empathy as a general trait are available, but a measure of empathy with people with dementia, based on my model, could be developed. Similarly, my MAPDAQ questionnaire could be broadened to measure person-centred attitudes at greater depth and in a wider range of care situations than just aggressive behaviour. Observation of carers' interactions with people with dementia and the care approaches they adopted would provide rich data that could be explored in relation to the model. Further, content validation of the model could be undertaken using qualitative methods, for example, involving 'expert groups' such as those proposed by Norfolk, Birdi and Walsh (2007) to examine its components. The value of the model as a framework for education and training could be explored and resulting curricula evaluated, with both professional and family carers.

A further line of inquiry could be to explore further the possibility that some carers are 'naturals' who seem to 'get the hang of' care principles without previous training (Sheard, 2004). Do such people really exist and if so, what factors in their personality, background or experience have contributed to their empathic abilities and therefore their ability to promote

cognitive security? A line of inquiry such as this again implies a systematic way of identifying carers who are adept at enhancing cognitive security.

Finally, the components of my model may have wider applications. In the future, it would be interesting to explore their usefulness for understanding care principles with other groups of vulnerable people, such as people with learning difficulties or severe enduring mental illness.

SECTION 6 – CONCLUSION

In this thesis I have synthesised the findings from my published work and presented this synthesis via the presentation a model of the qualities essential for caring for people with dementia. At the centre of the model is the concept of cognitive security as a key underlying need of people with dementia. In order to maintain and enhance cognitive security, carers must demonstrate empathy with the person, person-centred attitudes and a compassionate approach. I believe that my model is relevant to both professional and family carers and may be applied in all dementia care settings. As such, I further believe that I am making a useful and original contribution to the understanding of principles of care for people with dementia.

My model has relevance as a means of conceptualising and analysing dementia care and as a framework for education and training. It suggests directions for future research to develop ways of assessing carers' caring qualities and how these may be developed further. At the same time, it highlights some of the challenges to enhancing care for people with dementia. It shows that quality care requires carers to possess sophisticated cognitive, emotional and interpersonal qualities specific to dementia care settings and above all, positive attitudes and motivation. While some professional and family carers are 'naturals', many struggle with the interpersonal aspects of the caring role. With rising numbers of people with dementia worldwide, improving the quality of care is an urgent necessity.

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APPENDIX 1

D Pulsford Chronological List of Submitted Published Work and Indication of Contribution

Pulsford D (1997) Therapeutic activities for people with dementia -- what, why... and why not? *Journal of Advanced Nursing* 26(4): 704-9.

A literature review of research into the provision of activities for people with dementia exploring the range and types of activity, the value of activities and the role of staff attitudes in determining whether activities are carried out in formal care settings.
(DP 100% authorship)

Pulsford D Rushforth D Connor I (1999) Does play demean people with dementia? *Journal of Dementia Care* 7(5): 14-16.

A paper derived from a small-scale ethnographic study exploring the value of play-based activities for people with dementia in terms of engendering cognitive security in participants. Role of staff attitudes and communication strategies in facilitating such activities addressed.
(DP lead author and project lead, no grant; approx. 80% authorship)

Pulsford D Rushforth D Connor I (2000) Woodlands therapy: an ethnographic analysis of a small-group therapeutic activity for people with moderate or severe dementia. *Journal of Advanced Nursing* 32(3): 650-7.

A paper reporting on the overall findings of the above research study.
(DP lead author and project lead; approx. 80% authorship).

Pulsford D & Duxbury J (2006) Aggressive behaviour by people with dementia: a review. *Journal of Psychiatric & Mental Health Nursing* 13(5): 611-618

A literature review of published work related to nurses' and care staff's management of aggressive behaviour by people with dementia.
(DP lead author; 80% authorship).

Pulsford D, Duxbury J & Hadi M (2011) A survey of staff attitudes and responses to people with dementia who are aggressive in residential care settings. *Journal of Psychiatric and Mental Health Nursing* 18: 97-104

Quantitative findings from a small-scale research project funded by a £10,000 UCLAN grant.
(DP lead author and co-investigator; 75% authorship).

Duxbury J, Pulsford D, Hadi M & Sykes S (2013) Staff and relatives perspectives on the aggressive behaviour of older people with dementia in residential care: a qualitative study. *Journal of Psychiatric and Mental Health Nursing* 20: 792-800

Qualitative findings from the above project derived from interviews with staff and focus groups with relatives of residents.
(DP co-investigator and drafted first version of paper: 50% authorship).

APPENDIX 2 - D PULSFORD COMPLETE PUBLICATIONS LIST

- Pulsford D & Thompson R (2013) *Dementia: Support for Families and Friends*. London: Jessica Kingsley Publications.
- Duxbury J, Pulsford D, Hadi M & Sykes S (2013) Staff and relatives perspectives on the aggressive behaviour of older people with dementia in residential care: a qualitative study. *Journal of Psychiatric and Mental Health Nursing* 20: 792-800
- Pulsford D, Crumpton A, Baker A, Wilkins T, Wright K & Duxbury J (2013) Aggression in a High Secure Hospital: Staff and Patient Attitudes. *Journal of Psychiatric and Mental Health Nursing* 20(4): 296-304
- Pulsford D, Jackson G, O'Brien T, Yates S & Duxbury J (2013) Classroom-based and Distance-learning Education and Training Courses in End of Life Care for Health and Social Care Staff: A Systematic Review. *Palliative Medicine* 27(3): 221-235
- Pulsford D, Duxbury J & Hadi M (2011) A survey of staff attitudes and responses to people with dementia who are aggressive in residential care settings. *Journal of Psychiatric and Mental Health Nursing* 18: 97-104
- Pulsford D (2009) Fighting back: Why are people with dementia sometimes aggressive and how should we respond? *Signpost* 14(1): 36-39
- Thompson R, Hope K & Pulsford D (2009) More training, yes, but don't forget education. *Journal of Dementia Care* 17(4): 26-30
- Duxbury J, Hahn S, Needham I & Pulsford D (2008) The Management of Aggression & Violence Attitude Scale (MAVAS): a cross-national comparative study. *Journal of Advanced Nursing* 62(5): 596-606
- Hope K, Pulsford D, Thompson R, Capstick A & Heyward T (2007) Hearing the voice of people with dementia in professional education (Editorial). *Nurse Education Today* 27(8): 821-824
- Thompson R, Capstick A, Heyward T, Pulsford D & Hope K (2007) Involving people with dementia and their carers in professional education. *Journal of Dementia Care* 15(4): 26-28
- Pulsford D, Hope K & Thompson R (2007) Higher education provision for professionals working with people with dementia: a scoping exercise. *Nurse Education Today* 27: 5-13
- Pulsford D & Duxbury J (2006) Aggressive behaviour by people with dementia: a review. *Journal of Psychiatric & Mental Health Nursing* 13(5): 611-618
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- Pulsford D, Hall S, Keen T, Stokes F, Pusey H, & Soliman A (2003) What can Higher Education contribute to dementia care? *Journal of Dementia Care* 11(4): 27-8
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APPENDIX 3

The Submitted Published Work

Therapeutic activities for people with dementia — what, why... and why not?

David Pulsford BA RMN RNT CertCouns

Senior Lecturer, Department of Primary Health Care, University College of St Martin, Lancaster, England

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PULSFORD D. (1997) *Journal of Advanced Nursing* 26, 704–709

Therapeutic activities for people with dementia — what, why... and why not?

This paper reviews the literature pertaining to the provision of therapeutic activities for elderly people suffering from dementia. It relates both the provision of such activities, and the types of activity done, to the values and beliefs held by nurses and other professional carers. The range of therapeutic activities cited in the literature is explored, and reasons why activities are sometimes not offered to patients are discussed. Finally, research findings into the effectiveness and value of therapeutic activities for this group of people are reviewed.

Keywords: dementia, elderly people, therapeutic activities

INTRODUCTION

With rising numbers of elderly people suffering from dementia, and significant numbers of these still finding themselves in residential care settings, the question of what sort of psychological, as opposed to physical, care that such people can expect is becoming ever more pertinent. An increasing amount of literature has focused on the provision of therapeutic activities for people with dementia in residential settings, and the range of activities employed by nurses and others in the care of those with dementia has expanded greatly. On the other hand, provision of therapeutic activities as an integral part of nursing care in these settings is still by no means universal, and many elderly people with dementia will still spend their days clean and well fed, but unstimulated and inactive. This paper will concern itself with the literature on therapeutic activities for elderly people with dementia; discussing the range of activities that have been described in the literature, and research into their effectiveness, and will consider reasons why therapeutic activities are often not done. Initially, the value systems held by nurses and other professional carers which govern the range of thera-

peutic activities that may or may not be undertaken will be considered.

PROFESSIONAL VALUES AND THEIR INFLUENCE ON THE PROVISION OF THERAPEUTIC ACTIVITIES

Few areas of nursing care are as subject to the values, beliefs and attitudes of individual nurses as is the area of working with elderly people with dementia. Many tales have been told about poor or neglectful care given by nurses with 'bad attitudes' and much research has been done to identify and change attitudes of nurses in these settings (e.g. Treharne 1990, Alfredson & Annerstedt 1994). Both the provision or otherwise of therapeutic activities, and the type of activities provided if they are provided at all, is largely a function of the values, beliefs and attitudes of staff. These can be identified from the answers that nurses might give, either explicitly or implicitly, to the following three basic questions.

How do we regard people with dementia?

One answer to this question could be: 'as people like ourselves'. This assertion formed a fundamental part of the philosophy of 'cosmic nursing' (Goodwin & Mangan 1990). This movement embraced the concept of normalization fiercely, advocating levels of risk-taking in both the

Correspondence: David Pulsford, Department of Primary Health Care, University College of St Martin, Ashton Road Site, Lancaster LA1 5AX, England.

organization of care and in the provision of activities that went beyond what many nurses would regard as safe. As a value system it was seductive, but the inherent conservatism of most nurses, health care managers and, indeed, residents, along with a lack of empirical evidence as to its benefits, has led to its failure to catch on (Adams 1996).

There are other possible drawbacks to taking the view that elderly people with dementia are 'people like ourselves'. In important ways they are evidently not like the rest of us. In particular, it is doubtful whether they can, or should, be expected to take responsibility for their actions (Hillan 1993). If nurses do take the view that a demented person is capable of doing the things that they (the nurses) do, and the person fails, then nurses sometimes have a tendency to blame the person. Relating this to the provision of activities, nurses may insist on residents doing things that are not appropriate to their abilities, or to their interests, and then become discouraged and hostile toward them when the activity breaks down.

The second answer that can be given to the question, 'how do we regard people with dementia' is: 'as ex-people'. This view was expressed by a woman of my acquaintance who said that she was reluctant to visit her grandmother, suffering from Alzheimer's disease, because 'it isn't really her'. A number of writers have focused on how some relatives experience bereavement reactions when a loved one contracts dementia, through the loss of the sufferer's previous personality (e.g. Riggans 1992).

If such an attitude helps relatives come to terms with the devastating fact of dementia, it is perhaps not wholly to be condemned. The dangers of taking this point of view are, however, clear. At best, it obviates the need for therapeutic activities to be done at all. At worst, it leads to neglect and abuse of demented older people, or the attitude, 'It is like looking after babies, isn't it?' (Goudie 1990).

A third way of regarding people with dementia is: 'as people with disabilities'. This value system has the advantage of retaining the humanistic philosophy that people with dementia are worthy of respect, can experience emotions and will appreciate activity; while recognizing that they have serious disabilities which will influence the nature, extent and outcomes of the activities that they can undertake. Many of the more innovative activities discussed in the recent literature either explicitly or implicitly appear to embrace this value system.

Who are we most concerned to help?

The answer that most nurses would give to this question is, of course, 'the person with dementia'. But it is not the only possible answer. An equally plausible answer could be, 'the person's relatives/carers'. Keady (1994) has suggested that the focus of work in the area of dementia in recent years has been on the needs of carers rather than sufferers. Nurses working in respite or day care settings may particularly find themselves drawn to this point of

view, and regard their role as being to provide a 'sitting' service, with activity for the person a low priority.

Another answer that could be given by nurses to the question posed above is: 'ourselves'. Sometimes, the predominant value in a unit is for the staff to protect themselves, or to make life easier for themselves. Evers (1981) used the term 'minimal warehousing' to describe the care given to many demented residents, and Robb (1984) noted that often the main concern of staff was to get as much done as possible in the first three or four hours of a shift, with obvious implications for the provision of therapeutic activities.

What are our goals?

The implied goals of care of nursing staff will also have a bearing on the provision of therapeutic activities, and the emphasis given to different types of activity. Again, a number of possibilities present themselves. It could be that the goal of care held most valuable is to maintain the person in, or restore the person to the community (Zarit 1980), or failing that, to maintain or restore his or her level of cognitive functioning to as great an extent as is possible. Taking this view is likely to influence the therapeutic activities deemed suitable, with 'restorative' activities such as reality orientation being preferred. Another possible goal is maximizing the person's independence in activities of daily living. This will lead nurses to prioritize self-care and teaching activities. A third goal may be to enhance the person's quality of life. This rather amorphous goal is likely to lead to a range of activities with no real restorative purpose to them, but with enjoyment as a main aim. Yet another goal could be to give what Nolan *et al.* (1995) call 'good geriatric care', which translates: physical care to a high standard with psychological or social care given a low priority. All in all, the point is hopefully made that the provision of therapeutic activities with this client group is in essence a function of the way that care staff individually and collectively regard those in their care, and what they see as their purpose and goals in giving care.

THE RANGE OF THERAPEUTIC ACTIVITIES FOR PEOPLE WITH DEMENTIA

A wide range of therapeutic activities have been described in the literature as having been employed with this client group. This range can be usefully divided into three broad categories.

Social and diversional activities

A whole range of everyday activities can be used with people with dementia. Activity programmes may include exercise sessions, quizzes, sing-alongs, bingo, cooking, gardening, church services, crafts, puzzles, newspaper discussions and trips out, as well as many other things

(Conroy 1992, Turner 1993). The stated purpose of such activities is to encourage activity, interaction, and enjoyment. A number of the activities listed are, of course, activities that may be enjoyed by staff as much as by patients, and some imply a reasonable level of cognitive intactness for the person to appreciate them. To this extent, they may be said to emanate from a view of people with dementia as being 'people like us'. Other activities may be adapted for those with greater levels of intellectual decline, thus coming from a value system that views sufferers as 'people with disabilities'.

Cognitive therapies

A number of specific cognitive therapies have been developed that aim to have some sort of restorative effect on older people with dementia (see Hitch 1994 for a succinct introduction). Reality orientation specifically aims to arrest or reverse aspects of cognitive impairment in sufferers of dementia, while reminiscence, life review and validation therapy all aim in their pure forms to enhance mood and cognitive and behavioural functioning. A recent addition to the field is resolution therapy (Goudie & Stokes 1989).

'Alternative' therapies

A number of new approaches have also been reported that may be regarded as 'alternative' in that they are specially designed for people with moderate or severe dementia and have as their broad aims such humanistic goals as helping the person reach his or her potential, and enhancing the person's quality of life. They emanate very much from the value system of regarding patients as 'people with disabilities', and staff undertaking such activities will be doing things that would not normally be part of their own everyday lives. Examples of such activities reported in the literature include the use of Snoezelen multi-sensory rooms (McKenzie 1995), the therapeutic use of dolls (Ehrenfeld & Bergman 1995), 'orientation by seasons' (Bender 1995) and 'inter-acting' drama therapy (Agnew 1994).

WHY THERAPEUTIC ACTIVITIES?

Within the broad question of which value systems nurses and care staff should hold is embedded the specific question: why should nurses do therapeutic activities with people with dementia? A number of answers to this specific question are given in the literature, and the question becomes particularly important when one considers the evaluation of therapeutic activities, for any scientific evaluation should address the question: does this activity actually achieve its purpose? We will consider the range of possible purposes of therapeutic activities, and activi-

ties that have been recommended as suitable for each purpose, and return to the question of evaluation later.

To enhance mental state, or arrest mental decline

This may be regarded as the 'holy grail' of dementia care. In the absence of any physical or pharmacological therapy for dementia, a reliable psychological method of improving mental state would be invaluable. The main approach in this category is reality orientation (RO) (Hitch 1994), in both its 24-hour and classroom versions. Other therapeutic approaches have been cited in the literature as having a restorative effect, including reminiscence (Hitch 1994).

To reduce behaviour problems

A number of authorities suggest that the provision of activity can reduce the incidence and disruptiveness of behaviour problems such as wandering, agitation and shouting (Stokes 1990, Allan 1994, King & Watt 1995, Molasiotis 1995), by reducing boredom, channelling physical energy and providing distraction. Certainly, one sometimes observes what seems to be a relationship between an unstimulating environment and agitated or wandering residents, with nursing staff putting much energy into retrieving the wanderers or persuading them to sit down again, although there is nothing for them to sit down for.

To improve residents' quality of life

Most of the specific therapeutic activities described in the literature with aims that, broadly speaking, come under this category, are expressed in humanistic or person-centred terms. Nolan *et al.* (1995) state that the aim of therapeutic activities should be to raise residents' self-esteem, and Turner (1993) sees the goals of activity nursing as being stimulation and enjoyment, as well as enhancing cognitive functioning. For some workers, the goal of improving functioning or mental state becomes irrelevant, and aims such as socialization or promoting awareness of others are cited. Agnew's (1994) description of drama therapy urges nurses to consider the process of interacting with people with dementia rather than the product; the activity as an end in itself is what is important. Bleathman & Morton's (1992) description of validation therapy groups highlights the effectiveness of their techniques in encouraging socialization and self-expression while the group is in progress, and contrasts the participants' behaviour within the group with their apparently unchanged mental state and behaviour in the time between the weekly meetings. In similar vein Woods *et al.* (1992) in their study of reminiscence take as their dependent variable interaction within the group, rather than looking for improvements outside the group. Elliott & Milne (1991), in their study of the benefits of PAT-dogs on a continuing care ward took as their outcome measures interactions with others made

by patients while the dog was present. This philosophy was summed up by Norris (1986), who wrote:

To hold the attention of a confused old person who spends most of their day wandering round the ward mumbling incoherently, for 10 seconds, can be seen as a remarkable achievement when compared with what would otherwise be the norm for that person.

To enhance staff morale and attitudes

It is sometimes suggested that the real benefit of therapeutic activities for people with dementia lies less in the activity itself than in the indirect path of enhancing the morale, attitudes and personal knowledge of their patients by care staff, with consequent improvements in the overall care that patients receive. Reality orientation and reminiscence have been particularly cited as having this benefit (Schwenk 1981, Jones 1988). It could be argued, of course, that it should be unnecessary to impose therapeutic activities that may have no intrinsic value on residents simply to achieve a quality of care from staff that should be there anyway.

WHY ARE THERAPEUTIC ACTIVITIES NOT DONE?

Despite the many innovative ideas for therapeutic activities reported in the literature, it is still the case that the provision of these activities for residents with dementia is by no means universal (Nolan *et al.* 1995, Armstrong-Ester *et al.* 1994). Many nurses and care staff will cite practical or organizational reasons for this state of affairs. Most commonly cited is lack of time, or shortage of staff. However, Armstrong-Ester *et al.*'s (1994) study of interaction between nurses and residents was deliberately carried out at times of the day when there were few physical or house-keeping tasks to do, and they still found minimal interactions, and an absence of formal therapeutic activities. Perhaps a better excuse for staff to give might be a lack of 'quality time'; the heaviness and the emotional strain of the physical work of caring for such dependent people may leave nurses with too little emotional energy for meaningful interactions with patients. Sometimes, also, nurses say they lack time when they really mean that they feel they lack the skills or confidence to carry out therapeutic activities. There are occasions when tidying the laundry cupboard can become a very attractive proposition for a nurse faced with the alternative of spending an hour doing group activities! A final practical reason given is that therapeutic activities are the job of occupational therapists. But Nolan *et al.* (1995) point out that occupational therapists also often eschew therapeutic activities in favour of carrying out functional assessments. In summary, few of the practical reasons given for the lack of therapeutic activities in many residential units can be justified.

To find the real reason why therapeutic activities are often absent we have to return to the values and beliefs of care staff. Too few see sufficient value in carrying out this kind of work. As was reported above, some care staff have as their main aim getting the basic work done as quickly as possible. Armstrong-Ester *et al.* (1994) opined that nurses make strangers of their patients, eschewing the value of getting to know them as people, and concentrating on doing things to them, these things being exclusively physical care tasks.

In other cases, one can identify elements of what I call 'all or nothing thinking'. This viewpoint was expressed to me by a ward sister on a continuing care ward when I told her that a student nurse doing a placement on her ward could play the guitar, and I had suggested that she bring it in to do singing sessions with the patients. The ward sister's response was, 'I'm not sure that's a good idea. Only two or three of them are likely to respond. She (the student) might get discouraged'. The sister's belief seemed to be that as only a few patients would respond, the activity was not worth doing at all. A variation of this way of thinking can sometimes be found in units that decide to implement activity timetables. Typically, the staff will devise elaborate and extensive programmes filling many hours of the day, and post comprehensive timetables up on the day-room wall. Within a few days it becomes clear that the programme set is far too ambitious to be implemented in full, but instead of modifying their programme to something more modest and achievable, the staff think: 'This is impossible; therapeutic activities just can't be done here'. The whole programme collapses, and often just the timetable remains, fading on the wall. Whether 'all or nothing thinking' represents a lack of logic, or is another example of nurses protecting themselves from too close psychological contact with their patients is an open question.

A final reason that could be given by nurses for not doing therapeutic activities is that they perceive no benefit in such activities for the residents. This is, of course, an empirical question, and leads us on to research aimed at evaluating therapeutic activities.

THE EVALUATION OF THERAPEUTIC ACTIVITIES FOR PEOPLE WITH DEMENTIA

Although a body of literature has developed, from the fields of psychology and occupational therapy as well as nursing, there are still many unanswered questions around the evaluation of therapeutic activities for those with dementia. Many forms of activity have been thinly researched, and many of the studies that have been done have been small-scale, or have methodological inadequacies, or both. One fundamentally problematic question is that of finding suitable outcome measures. Some researchers have used standardized instruments which measure cognitive

functioning, such as the CAPE (Pattie & Gilleard 1979), and see the success of an intervention in terms of a long-term improvement in functioning. Others have looked for improvements in behaviour and social interaction both during and following a therapeutic activity (i.e. Elliott & Milne 1991). Still others have seen such goals as being too ambitious, and have looked for comparisons of patients' mood, interactions and awareness during activities with how they appear at other times (Bleathman & Morton 1992, Woods *et al.* 1992). Clearly, the outcome measures, or criteria for success of an activity that a particular researcher adopts will be a function of the value system of that researcher. A further difficulty that all researchers in this field must face is that it is often impossible to directly ask severely demented people for their subjective reaction to activities, or to ask them to fill in standardized questionnaires, and often their enjoyment and personal gain from an activity has to be assumed from other data.

These methodological and philosophical problems have contributed to lukewarm findings in outcome studies published in recent years. Reality orientation has by and large not lived up to its ambition of counteracting cognitive decline (Woods 1992), and reminiscence has also been found to have few tangible benefits in terms of long-term change in patients' cognitive abilities or behaviour (Thornton & Brotchie 1987). Validation therapy has also so far proved to be ineffective at promoting long-term gains (Bleathman & Morton 1992). Some small-scale studies have suggested modest gains in functioning from more general social or diversional activities (Elliott & Milne 1992, Conroy 1992, Turner 1993), but the slight nature of the benefits found and methodological difficulties with the studies must limit their interest for practitioners. Overall, the suggestion that therapeutic activities can improve behaviour or cognitive functioning (or, by implication, reduce behaviour problems), is not supported by the literature.

There is better evidence that therapeutic activities can change mood, behaviour and even cognition for the duration of the activity (Bleathman & Morton 1992, Woods *et al.* 1992). Whether this is a gain worth striving for is, of course, a function of the values held by the practitioner. Does it matter if a demented person cannot remember five minutes after a therapeutic activity that the activity has taken place? Can you honestly remember what you did last Thursday evening? The scale is different but the principle is surely the same. The fact that we have faulty memories of the things that we have done surely does not invalidate those things. But many care staff working with demented people have different values, and can easily get discouraged if they do not see long-term gains from the activities that they facilitate. The fact that we cannot cite research to firmly show that long-term gains can be achieved by doing such activities will do little to encourage them to persevere.

CONCLUSION

In this paper we have examined the range of therapeutic activities that have been reported in the literature as being suitable for people suffering from dementia, and discussed the factors involved in care staff involving themselves in such activities. An overall theme of the argument has been the role of values held, individually or collectively, by care staff in mediating whether they do therapeutic activities with those in their care, and the type of activities undertaken. We have briefly discussed the research literature into the effectiveness of therapeutic activities with this client group and have concluded that those who are doubtful about the long term effectiveness of such activities will find little in the literature to convince them of their benefits.

At the end of the day, we come back to values. Do we, or do we not, value providing therapeutic activities for people with dementia? The author has hinted at his own values obliquely during the course of this paper. Crump (1991) is less coy: indeed he views the lack of provision of therapeutic activities for these people as being tantamount to abuse. All those who work with older people with dementia should examine their values, and their professional practice, and ask themselves the fundamental questions posed earlier in this article: How do I regard people with dementia; Who am I here to help; and What are my goals when working with a demented person? And, in the end, is it enough for health care professionals to keep the bodies of institutionalized old people alive when those same professionals have contributed to driving out their souls?

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Does play

Many people with dementia respond positively to play-based activities – but their use remains controversial. Describing their own group work and its evaluation, David Pulsford, Irene Connor and David Rushforth argue that people with advanced dementia gain cognitive security from these activities, and may not see them as “play” in the same way we do.

David Pulsford is senior lecturer in mental health nursing, St Martin's College, Lancaster; Irene Connor is staff nurse, Woodlands View Day Hospital, Lancaster Moor Hospital; David Rushforth is lecturer in mental health nursing, School of Nursing, Midwifery and Health Visiting, University of Manchester.

demean people with dementia?

The value of purposeful recreational activity as a means of promoting well-being in people with dementia is now firmly established. The range of therapeutic approaches that may be used with people with moderate or severe dementia is rapidly growing. Among the newer approaches are play-based activities. These include games, experiences and toys that are normally associated with young children. The use of such activities is controversial. Proponents believe that they are a useful way of enhancing well being. Opponents feel that they demean older people, and are undignified. In this article we explore the use of play-based activities in dementia care. Evidence is drawn from an ongoing research project to evaluate a sensori-motor group therapy for people with dementia, which includes play-based activities.

Play-based activities in dementia care

A number of professional carers have written about their experiences with play-based activities. Such activities are often used as part of small group therapies. Bryant (1991) discusses sensory integration groups that included play-based activities such as ball and balloon games, and the use of long ribbons. Arno & Frank (1994) describe groups for "wandering" nursing home residents that involved ball games and busy boxes. Crichton (1997) devised a therapeutic approach named JABADAO, which is based on dance and movement and makes use of balloons, tug-of-war games and throwing cushions. Ehrenfeld & Bergman (1995) give an account of their efforts to introduce dolls into a residential setting as a means of encouraging interest, interaction and pleasure and Heywood (1994) describes attempting to engage and amuse a friend with dolls, a toy dog and other games (See also Sheard 1999.)

Impressionistic evaluations of these approaches suggest that play-based activities can be successful at focusing attention, interaction and pleasure in people with advanced dementia. To this evidence may be added the findings of our own research.

Woodlands Therapy

We have established a small-group therapeutic activity that takes place in a multi-sensory environment (MSE), known as Woodlands Therapy (WT). Our approach differs from other published accounts of the use of MSEs, which involve working with individual people



Play-based activities are best facilitated by staff who embrace a playful approach, and who recognise and respect people's individual likes and dislikes.

(eg Dowling *et al* 1997; Hope 1998). We work with groups of between four and six people, alternating the sensory experiences of the multi-sensory equipment with play-based activities such as ball and balloon games, playing with party blowers, blowing bubbles, dolls and other soft toys. Interactive Furbies (microchip-controlled talking toys) are a new addition to our repertoire!

We have been evaluating our approach using methods derived from ethnography (Hammersley & Atkinson 1995). This is the research approach used by anthropologists, and involves participant observation to describe and understand the culture and dynamics of a group of people. Five WT sessions were recorded on videotape. Reviewing the tapes has enabled us to analyse the responses of people to the specific activities in WT; examine factors that influence their responses; and observe facilitation strategies deployed by staff during sessions.

Overall, the play-based activities promoted considerable amounts of attention, participation and comment. All people appeared to derive enjoyment from at least some of the play-based activities. For instance, one game of balloons lasted for a full 12 minutes and provided one of the most lively and good humoured sequences on the videotapes. The dolls and soft toys also proved valuable. One lady became very attached to a battery-

operated parrot, which repeated back what was said to it. She asked after the parrot at the beginning of each session and talked to it at length, chuckling at the responses. Another person liked a rather garish fluffy duck, which sang nursery rhymes when its wing was pressed. Most people liked holding a large life-like baby doll, borrowed from one of our children. Best of all was a small, battery-operated dog, which walked across the floor. All participants in WT have found it fascinating.

Most people disliked some aspect of the play-based activities. One person, from a more middle-class background than the others, disliked ball games, and would register her disapproval by throwing the ball into a corner. People had individual likes and dislikes regarding the soft toys, and we had to learn which toy to offer to which person.

Despite their simplicity, activities were not always understood. People did not always understand the rules of the game when playing catch. They would catch a ball but not throw it on to someone else unless prompted. Balloon games went better, as the cognitive demands were fewer; people simply had to hit a balloon and it would float off to another member of the group.

The role of staff was crucial; activities were less important than the way they were facilitated. Perrin (1997) believes that staff need a playful attitude when working with people with advanced dementia. This was illustrated by an outgoing and bubbly student nurse who facilitated one session, and got a much better reaction from using party blowers than other staff. She brought a greater sense of fun to the activity; people responded with laughter and approving comments – and a great deal of noise!

All in all, our research suggests that play-based activities can promote enjoyment and well-being in people with advanced dementia. They are most effective when facilitated by staff who themselves embrace a playful approach, and who recognise and respect people's individual likes and dislikes for different activities or experiences.

The debate about play-based activities

Although there is growing evidence that play-based activities can promote well being, some people still find their use disturbing. There seem to be two main reasons for this. Firstly, there is the fact

that play-based activities are more or less imposed on people with dementia. In our society, adults can choose to indulge in children's games, for example at a family party, and many adults gain pleasure from possessing children's toys such as dolls or teddy bears. Society has more of a problem with adults making other adults act in a childlike fashion. One example of this is the use of "icebreakers", short exercises derived from children's games, on some training courses. Some participants in such exercises feel demeaned and insulted by the experience (Anderson 1992).

Secondly, there is the sense of loss we feel when regarding people with dementia. We yearn for them to be as they were, and for us to be able to interact as before, as adult to adult. In a poignant passage from his memoir of his wife, the novelist Iris Murdoch, John Bayley describes how he tried to interest his wife in a collection of ingenious palindromes, without success. She on the other hand would watch animated cartoons on children's TV with "something approaching glee" (Bayley 1998). The image of a one-time professor of philosophy and Booker prize-winning novelist watching children's TV jars against our sense of human dignity.

It may be asked whether dignity and well being are necessarily the same concepts. How often do we indulge in activities which enhance our subjective sense of well-being, but which are not necessarily dignified? Is it ethical for us to deny people with dementia the opportunity to enhance their well being in undignified ways when we delight in doing so ourselves?

Even if it is accepted that being active and undignified is better than being inactive and dignified, one may still question the use of children's toys and games to promote activity in older people with dementia. The detractors argue for age-specific activities, regarding these as being less demeaning. Our answer to this criticism derives from our theoretical explanation of the meaning of play-based activities for people with moderate or severe dementia.

The meaning of play-based activities for people with advanced dementia

There have been other attempts to explain play-based activities from the point of view of the people with dementia who participate in them. Perrin (1997) offered an explanatory framework based on the ideas of Jean Piaget. She hypothesised that people with advanced dementia have returned to Piaget's sensory-motor stage of cognitive development. They therefore respond to their environments as very young children would, and

If more of us could see that people with advanced dementia are not demeaned by play-based activities, but find them comprehensible and comforting, the well-being of those we work with could be further enhanced

are engaged by similar activities and experiences. Ratcliffe (1997) believed that the term "play" was a misnomer: a person with dementia who liked cuddling a baby doll was not playing, but regarded the doll as a real baby. She was therefore satisfying a basic human need to nurture and care for another.

These views are not entirely convincing. It seems to us unscientific for Perrin (1997) to transfer ideas from one area of investigation in human developmental psychology to another, without the research evidence to back them up. Ratcliffe's views of how people with dementia regard dolls may be correct in some cases, but the people who took part in WT did not believe that the dolls and toys were living things. A comment from the person who liked the toy parrot shows that she regarded the parrot in a complex way: "I like to hear him talk. He tries to say what you say. I have to keep him in mood, because he'll get lazy. It must be batteries or something inside. If I don't talk to him he'll get lazy."

Our own explanation for the value of play-based activities is that such activities induce cognitive security in people with advanced dementia. Such people are like the rest of us in that they have a basic desire to understand their physical and social environments. Play-based activities and experiences are more likely to be understandable than more complex stimuli from the adult world. They involve bright colours, simple actions, familiar images. Well being is enhanced as much by the provision of a comprehensible environment as by the intrinsically pleasurable nature of the activities or stimuli.

The cognitive security theory implies that people with dementia are regarding play-based activities in a different way from the way we see them. They may well not regard such activities as "play" in our sense of the word. Consequently, they do not feel demeaned by taking part. Instead, they gain well being from being

able to respond in a positive way to comprehensible experiences presented by sensitive and empathic facilitators.

Conclusion

In his book, John Bayley describes watching *Teletubbies* with his wife, Iris Murdoch, and recounts the enjoyment that Ms Murdoch derived from this TV programme. Two messages come from this little vignette. Firstly, Ms Murdoch, not known for her childish nature, was not "playing" when she watched *Teletubbies* and other children's TV programmes. She enjoyed *Teletubbies* because she could understand its bright, clear sounds and images, and respond to it at some level.

Secondly, this episode illustrates the fundamental humanity of her husband, himself a retired Oxford professor, who could bring himself to offer his wife this kind of stimulation, and attempt to enjoy it alongside her. Perrin (1997) believes that professionals are more likely to be disturbed by play-based activities than lay carers. If more of us could appreciate that people with advanced dementia are not demeaned by play-based activities, but find them comprehensible and comforting, the well being of those we work with could be further enhanced.

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Woodlands therapy: an ethnographic analysis of a small-group therapeutic activity for people with moderate or severe dementia

David Pulsford BA(Hons) RMN RNT Cert. Couns.
Senior Lecturer, Department of Primary Health Care,
St Martin's College, Lancaster

David Rushforth MPhil BA(Hons) RMN RNT Cert. Ed.
Lecturer, School of Nursing, Midwifery & Health Visiting,
University of Manchester, Manchester

and Irene Connor RMN
Staff Nurse, Oaklands Day Unit, Lancaster, England

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Woodlands therapy: an ethnographic analysis of a small-group therapeutic activity for people with moderate or severe dementia

This paper reports on an analysis of Woodlands therapy (WT), a sensory-motor therapeutic activity that aims to encourage interaction with people with moderate or severe dementia. The aims of the study were to examine: the responses of patients to the sensory experiences and play-based activities that make up a WT session; the factors that influenced their responses; and the verbal interventions employed by the staff who facilitated WT sessions. Methods derived from ethnography were used. The data comprised videotapes of five WT sessions, notes of other sessions, and discussions with staff involved with the approach. Thematic groups of patients' responses were formulated. WT mainly appears to engender the responses of attention, participation and comment. Factors that influence patients' responses are discussed. The findings indicate that staff facilitation strategies strongly influence patients' responses to WT. Verbal interventions made by staff are grouped in terms of their relative helpfulness for promoting positive responses to WT. Suggestions for practice are made for professional carers undertaking sensory-motor therapeutic activities for people with dementia.

Keywords: dementia, therapeutic activities, ethnography, multi-sensory environments, Woodlands therapy, nursing, day care

INTRODUCTION

The range of therapeutic activities for people with dementia is expanding rapidly. In a previous review Pulsford (1997) devised three broad groupings: cognitive therapies, social/diversional activities, and alternative, or

Correspondence: David Pulsford, St Martin's College, Bowerham Road, Lancaster, LA1 3JD, England. E-mail: d.pulsford@ucsm.ac.uk

sensory-motor, therapies. Woodlands therapy (WT) is an example of a sensory-motor therapy. WT is a structured group activity that takes place in a day hospital for older people with mental health problems. It is led by a nurse facilitator in a multi-sensory environment (MSE). The goal of WT is to encourage group interaction among people with moderate or severe dementia through the combination of recreational activity and sensory stimulation in the pursuit of enhancing the well-being of the participants.

The focus on well-being of people with dementia derives from the work of Kitwood (1997). In Kitwood's person-centred approach to dementia care he contends that the maintenance of personhood through the promotion of subjective well-being should be the principal aim of such care. Kitwood's focus on personhood may be seen as an application of the humanistic philosophy of Carl Rogers (Rogers 1967) to dementia care.

Kitwood argues that well-being is a function of the quality of interaction between the person with dementia and his or her professional carers. Activities such as WT may enhance well-being through providing a medium for social and therapeutic interaction between participants, and with the professional carers who act as facilitators. Enhanced well-being may be related to other benefits, such as reduction of difficult behaviour, and maintenance or enhancement of cognitive functioning.

This project reports on the verbal and behavioural responses of people with dementia to WT, analyses factors within WT that mediate patients' responses, and explores how these might contribute to our understanding of their well-being.

WT shares many common characteristics with a number of published accounts of sensory-motor therapies (Bryant 1991, Arno & Frank 1994, Robichaud *et al.* 1994, Ehrenfeld & Bergman 1995, Threadgold 1995, Crichton 1997). Their stated purpose is also to promote attention, communication, cognitive stimulation, socialization and enjoyment among patients. A variety of sensory experiences and motor activities are deployed, typically within a structured programme facilitated with a small group of patients. Play-based activities such as balloon or ball games, bubble blowing, or dolls and soft toys, may be used to promote social interaction.

Other accounts focus on the use of Snoezelen-type multi-sensory environments (Moffat *et al.* 1993, Pinkney & Barker 1994, Dowling *et al.* 1997, Hope 1997, 1998). Most researchers prefer MSEs as a setting for individual patients to experience either sensory stimulation or relaxation. Woodlands therapy builds on this approach. In WT, the multi-sensory environment becomes an adjunct to small-group recreational activity. WT makes full use of the electronic effects of the MSE and combines these with other sensory-motor and play-based activities initiated by the facilitators.

To date, research into sensory-motor therapies has largely focused on outcome measures that attempt to demonstrate the potential value of such therapies. These studies draw on quantitative methods to gauge outcomes such as cognitive enhancement, reduction of behavioural problems, or changes in mood and social interaction. The weight of the findings to date suggests that long-term cognitive or behavioural improvements are limited (Robichaud *et al.* 1994). Sensory-motor approaches may, however, be effective in enhancing well-being and communication while sessions are taking place (Dowling *et al.* 1997, Hammill 1997, Hope 1998, Perrin 1998).

Little attention has been paid to analysis of the *process* of sensory-motor therapies. This forms the subject of the present study.

THE STUDY

Purpose

This study aimed to use qualitative methods derived from ethnography to analyse and evaluate Woodlands therapy, with particular reference to what happens during WT sessions. Three specific research questions were considered:

- How do patients respond to the elements of WT?
- What factors influence the responses that patients make?
- What influences do the staff facilitators have on patients' responses?

The overall aim was to generate suggestions for practice for professional carers undertaking sensory-motor therapies with people with dementia.

Method

Procedure

Woodlands therapy is aimed at patients with moderate or severe dementia. Sessions last for up to 1 hour, and take place once or twice per week. A WT session comprises a sequence of activities and experiences drawn from a broad menu (see Figure 1).

Sessions are normally led either by the staff nurse responsible for developing WT, or by the first author. Other nursing staff, including student nurses, act as co-facilitators. The lead facilitator takes the group through a sequence of activities, normally alternating sensory and play-based experiences. All staff members assist the patients in participating in the activities.

Data collection

The main data that informed the study consisted of videotapes of five WT sessions. Reflective notes were also compiled from other WT sessions. In particular, a number

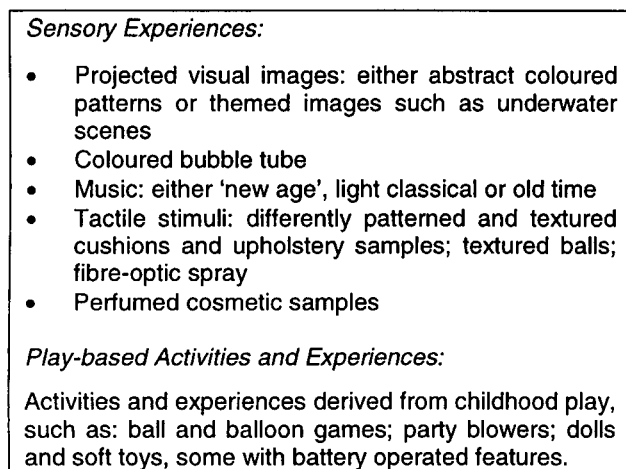


Figure 1 Menu of activities and experiences that may be included in a WT session.

of sessions took place during which staff took a passive, rather than active, approach to facilitation. These were to ascertain the reactions of patients to the electronic effects of the MSE alone, in the absence of interventions by the staff. Reflective discussions were held with the other staff involved with WT. Transcripts were made of the dialogue that took place during the videotaped sessions.

Sample

Each videotaped session was attended by four female patients. Three patients attended all sessions, one patient attended four sessions, and another a single session. These patients had been participating in WT for several months prior to the commencement of the study. The patients who participated were tested using the Mini-Mental State Examination (Folstein *et al.* 1975), and scored between 8 and 14, indicating moderate or severe dementia.

Ethical issues

In general it is argued that people with dementia are unable to provide informed consent to participate in research. This study is no exception. In such cases, stringent criteria are required and the evidence produced to satisfy local ethical committee standards (Wing 1991). The study proposal was assessed on the following criteria:

- Does the intervention ensure minimal risk of physical or psychological harm to patients?
- Can the research not be completed with competent patients?
- Are relatives fully informed and do they agree consent?
- Have the participants the right to object, verbally or behaviourally, and withdraw at any point in the intervention?
- Has an ethics committee approved the research?

These conditions were met in this study. Assurance was given to relatives that the videotapes would not be viewed

by anyone other than the author, and would be destroyed when data analysis had taken place.

Data analysis

The approach to data analysis was essentially descriptive and interpretative (Tesch 1991), in that it sought to describe and understand WT from the point of view of its participants, both patients and staff. Discourse analysis was used to identify the kinds of verbal interventions made by staff, and also to find clues about the patients' experience of WT. Copious reflective notes generated further commentary on the videotapes and transcripts.

Baillie (1995) believes that the qualitative researcher should aim for his or her findings to be trustworthy. A trustworthy study is one that has been conducted fairly, with conclusions that reflect the reality of the people being studied. This was an issue. The first author was both researcher and a principal subject of the research, as lead facilitator of WT sessions. Two strategies were employed to ensure the trustworthiness of the present study.

First, the use of videotapes assisted in accurate and complete reporting of the data sets. Two months elapsed between recording the tapes and watching them. This ensured that many details of the sessions had been forgotten, and the tapes could be analysed afresh.

The second approach used within the study was respondent validation (Hammersley & Atkinson 1995). Two of the day hospital staff read and commented on an early draft of the findings of the study, to check whether the author's conclusions concurred with their own experience. Their comments were incorporated into the final report.

FINDINGS

Patients' experience of WT

Scrutiny of patients' verbal and non-verbal behaviour during the video-taped sessions has suggested thematic groupings of patients' responses.

Rejection, characterized by overtly or covertly rejecting an experience or activity that is being presented. Overt rejection included patients refusing to participate in an activity, or stating negative opinions about an experience. Other rejection was more covert. For example, one patient disliked ball games, and would sometimes throw a ball that had been passed to her into a corner, rather than to another participant.

Non-attention: this is defined as a patient either attending to something other than the focus of the session at the time, or apparently not attending to any external stimulus. Dozing or sleeping come into this category.

Attention: this includes passively watching or listening to a session-based visual or auditory stimulus, or watching staff interact with other patients. The key feature of this

category is that, although the patient is being passive, the current activity of the session is uppermost in her mind.

Comment/participation: 'comment' refers to favourable verbal comments about a stimulus. 'Participation' refers to patients' active physical participation in activities initiated by staff.

Interaction: this category refers to a patient interacting verbally or non-verbally with another patient, rather than with staff. Examples of non-verbal interaction might be a patient throwing a ball to another patient, or handing another patient a stimulus object.

Initiation: this final category is defined as a patient initiating an activity herself, or making a suggestion for an activity or experience.

The most frequent responses recorded were attention and comment/participation. Rejection occurred occasionally when a patient refused to take part in a particular activity, or made it clear that she was participating unwillingly. Non-attention was uncommon; however, this was largely due to the efforts of the facilitators to maintain patients' attention, or to encourage participation and comment. Interaction was rare. Indeed, the patients tended to be rather intolerant of each other and of the behavioural foibles that resulted from other patients' dementing illnesses. Initiation was even less common, being limited to one patient enquiring after a particular soft toy that she favoured.

Factors influencing patients' responses

Patients displayed differential responses to different components of WT. Observation of the video-tapes, and consideration of the patients' medical and social histories, suggest a number of factors which will influence their experience.

Biographical factors: factors such as culture, social class, values and beliefs, likes and dislikes, and previous experiences, all appear to influence patients' responses to WT. For example, one patient disliked balloon and ball games, but enjoyed the light classical music tape that was often used to accompany the sessions. The dolls and soft toys prompted differing responses. One patient was very attached to a battery operated toy parrot, which repeated what one said to it. Another patient, who was fond of music, liked a large fluffy duck which sang nursery rhymes. Other patients were less enamoured of the soft toys, but would cuddle a large life-like baby doll. All patients enjoyed watching a small, battery operated dog, which could be made to walk across the floor.

Cognitive deficits: the cognitive deficits resulting from dementing illness affected patients' ability to participate in, and respond to, the experiences and activities of WT. The facilitators had to modify their interventions accordingly. Patients seemed not to understand the 'rules of the game' when playing games of catch. They would catch a

ball, but would often not throw it on to someone else unless prompted by staff. Group participation in the form of motor activity increased when batting balloons, as all the patients had to do was to hit a balloon that came their way, and it would float off to someone else.

If staff asked patients to comment on sensory experiences, the questions had to be put in very simple terms. If the activity was watching abstract patterns, it was quite sufficient to put the question 'What colours can you see?'. When tactile stimuli were being handed around and talked about, more response was engendered by asking patients to compare two stimuli than by asking them to comment on a single sample (e.g. 'Which of these is softer?', 'Which do you prefer?'). Comparing two stimuli was an easier intellectual task for most patients than trying to describe a single stimulus, with no point of reference on which to base their responses.

Sensory/motor deficits: a therapeutic activity that relies on sensory and motor stimulation is clearly going to be affected by patients' sensory-motor deficits. For example, two of the patients had a limited sense of smell, which curtailed the use of scents within the sessions.

Patients' social awareness and social skills: some patients had impaired social skills as a result of dementing illness. This affected their own, and other patients' experience of sessions. For example, one patient was very prone to perseverance, and kept uttering long, rambling monologues which were not appreciated by the rest of the group.

Facilitation decisions made by staff: this factor represented the greatest influence on patients' responses to WT. This was underlined by the informal experiment that was carried out in two or three WT sessions. In these sessions, staff deliberately took a passive approach to facilitation. The sessions consisted solely of patients watching the visual sensory stimuli provided by the MSE, which were changed periodically, and listening to music. Staff did not initiate any verbal interaction with patients, or present any play-based activities. The patients spent virtually the whole of these sessions in non-attention mode. They rarely looked at the visual stimuli, and initiated no conversation, either with staff or each other. Most spent the hour drifting in and out of sleep. It was clear that the MSE equipment alone was insufficient to maintain their attention.

Categories of staff interventions

Staff facilitation decisions are therefore very important for the success of WT. This finding led to the generation of a categorization scheme of verbal interventions made by staff during WT.

Questions which ask patients to express their views and feelings about aspects of their experience: e.g. 'Do you like these lights?', 'What do you like about...?', 'Which of these do you prefer?'. These interventions aimed to direct the

patient's attention towards a stimulus, and to facilitate the patient expressing her views about the stimulus.

Questions that ask patients to comment on aspects of their sensory experience: e.g. 'Does this cushion feel soft?', 'What colours can you see?', 'Which one feels nicer to you?'. These interventions again aimed to engage patients' attention, or elicit comment.

Patient-centred interventions: this category contained three broad types of intervention. First, staff used *paraphrases* or *reflections* of things said by patients (e.g. Patient: 'I love this music'; Staff: 'You love it, do you?'). Second, staff made *approving comments* on behaviour undertaken by patients (e.g. 'You're watching the bubble tube very intently, Doreen'). Third, staff would pay patients *compliments* on aspects of their performance (e.g. 'You're hitting that balloon well today, Edith').

Questions asking patients to provide information based on memory or intelligence: these were questions that asked more of patients than simply commenting on their immediate sensory experience. Some could be classed as general knowledge questions (e.g. 'What radio programme did this tune come from?', 'Do you know what this is made of?'). Others tried to elicit memories (e.g. 'Can you remember what we do when we come in here?', 'Did you have a teddy bear when you were young?').

Comments made by staff on aspects of the MSE experience: (e.g. 'I like it when the colours change, don't you?', 'This cat's extremely furry, isn't it?'). These interventions again aimed to facilitate attention or conversation.

Word play: occasionally staff interacted through using jokes, or word games, with the aim of introducing humour into the sessions ('Here's our spotty dog. We call him Stripe').

Interventions that assisted the management of a session: this category included the lead facilitator's introduction to a session, and simple managing or orienting comments: (e.g. 'Give this cushion a stroke', 'We'll look at one more thing before lunch time').

The above mentioned categories of intervention appeared to be differentially useful at furthering the aims of WT. Patients were able to respond more positively and constructively to some interventions than others. Overall, the categories of questions which ask patients to express their views and feelings about aspects of their experience, questions which ask patients to comment on aspects of their sensory experience, and patient-centred interventions, appeared to engender the most positive responses from patients.

The categories of questions asking patients to provide information based on memory or intelligence, comments made by staff on aspects of the MSE experience, and word play, did not elicit positive responses. Patients were rarely able to answer memory-based questions, and did not understand the staff's jokes or clever comments.

The following interactions serve to illustrate these points. On one occasion, the lead facilitator was interacting with Amy:

Lead facilitator: (Hands Amy two carpet samples) Have a feel of these two, Amy.

Amy: Deep carpet.

LF: Deep carpet?

Amy: This one's rather rough.

LF: It is rough, isn't it. Which one do you prefer?

Amy: Oh I like that one.

LF: You like that one the best?

Amy: For walking on.

LF: Oh aye, yes. It's very furry for a carpet, isn't it.

Amy: Yes.

LF: Let's try another one. What do you make of that one?

Amy: It isn't nice for walking on is that one.

LF: No?

Amy: No, it isn't nice at all, it's too stiff.

LF: You wouldn't like to walk on it in bare feet. Try this one.

Amy: That's better. Nice and soft. T'isn't too long.

LF: That's sorted all them out, then.

In this extract, the lead facilitator demonstrates an ability to keep within Amy's internal frame of reference (Nelson-Jones 1989). The questions ask Amy to comment on her experience, by paraphrasing Amy's words. The facilitator offers affirmative feedback which values her interpretations. Amy is enabled to participate fully in the interaction.

This passage may be contrasted with an interaction between Amy and a nurse new to this approach:

Nurse: Amy.

Amy: Yes?

Nurse: (hands her a cushion) Here you go. Have a feel.

(Amy strokes the cushion)

Nurse: It's lovely, isn't it. Like stroking an animal.

Amy: I don't like that, stroking animals, no.

Nurse: What sort of animal would have fur like that, do you think?

Amy: No, no... don't mention cats to me!

Nurse: Don't you like cats?

Amy: No.

Nurse: Why?

Amy: I don't know... just one of those things.

Nurse: Mm (strokes cushion). It's a nice colour, isn't it?

Amy: (gives cushion a perfunctory stroke) I don't think about cats, they scratch.

Nurse: Only if they're moulting.

(Amy looks away)

The nurse begins this exchange with a remark from her own frame of reference ('It's lovely, isn't it. Like stroking an animal'), which Amy responds to from her own frame of reference ('I don't like that, stroking animals, no'). Instead of acknowledging her expressed attitude, the nurse then asks a memory-based question ('What sort of animal would have fur like that, do you think?'). Amy is able to answer it, but the nurse is still unwilling to acknowledge her frame of reference. She tries to engage Amy in the sensory-motor activity (stroking the cushion), but Amy is still concerned with getting her views about cats expressed ('I don't think about cats, they scratch'). The nurse disputes Amy's attitude by presenting a perspective of her own ('Only when they're moulting'). Amy then concludes the interaction.

DISCUSSION

This study has indicated that patients mainly respond to the sensory and play-based activities that make up WT by displaying attention, or by participation or comment. In most cases, non-attention is uncommon, providing that staff facilitate actively. Overt or covert rejection is relatively infrequent. Patients have their own likes and dislikes regarding particular activities and experiences, but staff endeavour to accommodate these within sessions.

Interaction between patients and initiation of activities by patients is uncommon, but this finding is perhaps not unexpected given the degree of cognitive impairment exhibited by the participants. An analysis of the behaviour of nursing home residents with dementia at meal times (Sandman & Norberg 1988) similarly found low levels of interaction between the more severely disabled patients.

A clear finding is that the sensory experiences of the MSE were not sufficient on their own to promote attention, comment or participation. This was evidenced by the sessions during which staff deliberately took a passive role, resulting in extensive non-attention by patients. The electronic effects did not compensate for the lack of positive staff involvement. Mount & Cavet (1995) criticise MSEs for giving an impression of luxury and forward thinking to a care setting, while sometimes being used as a 'dumping ground' where patients can be left and ignored. This study shows that MSEs are only as effective as the staff who use them.

Indeed, the most significant factor related to the success of WT in promoting attention, participation or comment is the facilitation style adopted by staff. This finding echoes observations made by Perrin (1998), in her evaluation of JABADAO, a sensory-motor therapy based on dance and movement (Crichton 1997). This study demonstrates the need for active, directive and empathic facilitation of sensory-motor therapies, if these outcomes are to be achieved.

Kovach & Henschel (1996) and Perrin (1997a) equate active participation by a person with advanced dementia in an activity with that person experiencing enhanced well-being. Perrin (1997a) cites engagement theory (McFadyan 1984) as justification for this view. She believes that engaging with others, or the environment, is the route to optimum health for older people. We are more cautious in equating attention, comment or participation, related to an activity such as WT, with enhanced well-being. Patients sometimes participate in an activity unwillingly, and covertly reject the activity. Also, one cannot be sure that simply attending to a sensory stimulus is sufficient to promote well-being. Many people will attend to a television programme, not through enjoyment, but as a way of passing the time. One participant in WT remarked to her neighbour:

I always come [to WT sessions]. I just come in for coming's sake... I've seen it loads of times. I stop here till it's time for dinner in there. And then you haven't so long to wait for your dinner.

Further, this study was not an experimental trial of WT. No attempt was made to compare patients' reactions to WT with a control condition. Although our impression is that the reactions of participants to WT may lead to positive mental health outcomes, it is not possible to reach firm conclusions without carrying out a controlled clinical trial, with measurable outcomes.

The verbal interventions made by staff during WT sessions appear to be particularly significant in promoting attention, comment and participation. Interventions that seek congruence with the patients' views and experiences lead to more positive responses than interventions that emanate from the staff's point of view. Interventions that require memory or intellectual processing are also unhelpful.

These findings may be related to a number of theoretical frameworks. Carl Rogers stated that the basis of person-centred helping is for the therapist to display qualities of empathy, genuineness and unconditional positive regard (Rogers 1967). The effective interventions described above may be regarded as manifestations of these qualities by the facilitators of WT.

Kitwood (1997) related Rogers' principles to dementia care. He believed that effective communication with people with dementia depended on professional carers minimizing occurrences of malignant social psychology

and maximizing examples of positive person work. The less helpful communications noted in the present study included aspects of malignant social psychology, in particular *outpacing*, communicating with patients at too advanced an intellectual level; *invalidation*, ignoring or belittling the patient's views or feelings; and *imposition*, staff imposing their views on to patients. Such interventions failed to acknowledge the patients' needs and wishes, or make allowances for their cognitive disabilities. The more effective communications included examples of positive person work, such as recognition and validation. These interventions emanated from a more person-centred perspective.

A parallel may also be drawn with mainstream educational research into communication with pre-school children. Leach (1979) emphasizes the value of cognitive empathy, which fosters person-centred communication strategies such as paraphrasing or reflecting the child's utterances. She also states that adults should appreciate the limits of a young child's understanding, and tailor their interactions accordingly. There was some evidence that the staff, most of whom were parents, were applying transferable skills derived from their experience of interacting with young children when working with patients in a positive way. Participants in WT were regarded as adults, but allowance was made for their cognitive limitations.

This point leads us to consider the context of such interaction, that is the role of play-based activities and experiences for people with dementia. Perrin (1997b) espouses the value of such activities. She argues that people with progressive dementia move back through Piaget's stages of cognitive development, until they return to the sensory motor stage. Play based activities such as balloons, ball games, bubble blowing, dolls and soft toys are considered the most appropriate means of interacting with people with severe dementia, as they have their effect at the sensory motor level.

The evidence of the present study is that all patients in the video-taped WT sessions derived enjoyment from play-based activities. It was certainly the case that each patient disliked some aspect of the play-based activities and experiences, but staff made allowances for these individual differences. Play-based activities led to some of the most positive sequences on the video-tapes. One game of balloons lasted for 12 minutes, with more laughter and energy expended than in any of the other recorded sessions.

The notion that play-based activities and experiences may enhance well-being is controversial. It is felt by some that it is demeaning for older people to be made to participate in children's games (Perrin 1997b). Johnson (1998) believes that professional carers should look for age-specific ways of engaging with older people with dementia.

Our belief is that play-based activities promote cognitive security in people with advanced dementia. Play-based activities that are preferred by people with severe cognitive disabilities are characterized by bright clear images and colours, and simple, readily recalled actions. They are therefore understandable, at some level. It is questionable whether patients are actually 'playing' at all. They are simply taking part in an agreeable activity that they can comprehend and succeed at. By doing so, they may be experiencing enhanced well-being. Play-based activities provide a contrast to some age-specific activities that require greater levels of cognitive ability, and are consequently difficult for the person with dementia to fully participate in.

CONCLUSION: IMPLICATIONS FOR PRACTICE

A number of suggestions for practice may be made when undertaking sensory-motor therapeutic activities, of a similar nature to WT, with people with dementia.

Adopt an active and directive facilitative style

This study indicates that the goal of enhanced well-being can only be achieved if facilitators are active and directive. If staff are passive and detached during a therapeutic activity, that activity is unlikely to be successful.

Use person-centred principles when conversing with patients

Communication principles derived from the person-centred approach to counselling may offer a purposeful approach to communicating with people with dementia. Verbal attending skills such as paraphrasing and reflection aim to sustain the conversation within the patient's own frame of reference.

Use activities, experiences and verbal interventions that minimize the need for intellectual processing

Professional carers may overestimate the ability of a person with dementia to process information cognitively, or to retrieve previously learned material from memory. Staff that demonstrate cognitive empathy recognize their patients' limitations.

Use transferable skills derived from working with young children

One way of achieving the above aim is to employ activities, experiences and communication strategies that are effective with very young children. Play-based activities may enhance the patient's sense of cognitive security, and thus enhance well-being.

Finally, more research is needed, in the form of controlled clinical trials, in order to provide more rigorous evidence for the mental health benefits of WT, and other sensory-motor therapies, for people with advanced dementia.

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Aggressive behaviour by people with dementia in residential care settings: a review

D. PULSFORD¹ MPhil BSc RMN RNT & J. DUXBURY² PhD BSc RMN RN RNT

¹Senior Lecturer, Division of Mental Health, and ²Divisional Leader for Mental Health, Department of Nursing, University of Central Lancashire, Preston, UK

Correspondence:

D. Pulsford

Department of Nursing

University of Central Lancashire

Preston PR1 2HE

UK

E-mail: dpulsford@uclan.ac.uk

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Aggressive behaviour by people with dementia in residential care settings: a review

This paper considers the phenomenon of aggressive behaviour perpetrated by people with dementia in residential care settings. Aggressive behaviour is defined in the context of people with dementia, and the problem of ascertaining the incidence of aggression among people with dementia is discussed. The emotional impact of assaults on nurses and other professionals is highlighted, and differing perspectives on the causation of aggressive behaviour are considered. Management strategies derived from the physical/pharmacological; environment management; behaviour modification and person-centred approaches are reviewed. Our conclusion is that while certain strategies appear to reflect good and common sense practice, in particular those deriving from the person-centred approach, there is no clear research evidence for the general effectiveness of any one management approach, and each has drawbacks of a practical or ethical nature. There is also little empirical information about how professional carers actually manage aggressive behaviour in practice.

Keywords: aggression, behavioural and psychological symptoms, challenging behaviour, dementia, person-centred care, violence

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Introduction

There are today around 750 000 people in the UK with a dementing illness (Alzheimer's Society 2005), three times as many as those who have schizophrenia (SANE 2005). Dementia care is still, however, a relatively neglected area of mental health nursing practice. This is despite the considerable rewards of nursing this group of people, and also the challenges that nurses and other professional carers face in managing some of the consequences of dementing illnesses. One such challenge is aggression perpetuated by people with dementia against those who care for them. This paper will discuss the research literature related to aggression by people with dementia in residential care settings, highlighting issues for nursing practice, and directions for future research. It is based on a search of the

CINAHL, MEDLINE and PSYCHLIT databases, using the search terms 'dementia'; 'Alzheimer's disease'; 'aggression'; 'violence' and 'behavioural and psychological symptoms'.

Definitions

The terms 'aggression' and 'violence' both appear regularly in mental health nursing literature, and are used in various ways. A recent initiative, the NHS Zero Tolerance Campaign (NHS 2002), uses the term 'violence', which it defines as:

... any incident where staff are abused, threatened or assaulted in circumstances related to their work, involving an explicit or implicit challenge to their safety, well-being or health.

While this definition can be applied equally to the behaviour of people with dementia as to other groups, the term 'violence' seldom appears in dementia care literature. Two possible reasons may account for this. First, 'violence' seems to imply intentionality on the part of the perpetrator, a concept that is often difficult to apply to people with dementia (Gates *et al.* 1999). Second, 'violence' implies a degree of severity that again often cannot be applied (Astrom *et al.* 2004), although the emotional consequences for the recipients of such behaviour are not trivial (Gates *et al.* 1999). In contrast, the dementia care literature almost universally uses the terms 'aggression' or 'aggressive behaviour'. These terms are perhaps less emotive and pejorative and will be employed for the purposes of this paper.

The context of aggressive behaviour

Aggressive behaviour by people with dementia is categorized among the 'behavioural and psychological symptoms of dementia' (Turner 2005). The alternative term 'non-cognitive features of dementia' is also found in the literature (Karlsson 1996), while in the context of nursing care, the term 'challenging behaviour' is often used (Stokes 2000). Other examples of behavioural and psychological symptoms are wandering, agitation, shouting, hoarding, sexual disinhibition, eating disorders, inappropriate toileting, repetitive questioning, self-injurious behaviour and apathy (Turner 2005). Incidence of behavioural and psychological symptoms is high among people with dementia; Ballard *et al.* (2001) reported 86% among a UK residential care sample. Ascertaining the specific incidence and severity of aggressive behaviour is, however, not straightforward. Recent UK national surveys of violence and aggression in healthcare settings have not highlighted people with dementia (or older people in general) as a separate group (Department of Health 2002). There is also considerable evidence that the perception of care staff as to what constitutes challenging behaviour is subjective, and they often under-report incidents of aggressive behaviour perpetrated against them (Gates *et al.* 1999, Healthcare Commission 2005).

Several smaller-scale studies offer figures for the incidence of aggressive behaviour in residential care settings for people with dementia, but do not state clearly how this behaviour has been defined, or whether the aggression is directed towards care staff, family or other residents. It has also been observed that two apparently similar care facilities can experience very different rates of aggressive behaviour (Gates *et al.* 2003). The overall impression is of a high incidence of usually low-impact aggression among people with dementia. For example, Astrom *et al.* (2004), from a sample of 848 residential care staff, found that 11.4%

reported being exposed to aggression during the period of investigation; 4% received wounds and bruises and 2 staff consulted their general practitioners because of the incident. At the same time, more serious aggressive incidents occasionally occur, including self-harm (De Jonghe *et al.* 2005) and homicide (Hindley & Gordon 2000). Aggressive behaviour is more common among people with dementia than among older people who do not have dementia (Chou *et al.* 1996, Wystanski 2000), and aggression against family members is a major reason for the person entering residential care (Gilley *et al.* 2004).

Causes of aggressive behaviour in people with dementia

Aggression in people with dementia is a complex phenomenon, with several possible causative factors. First, the person may have a history of aggressive behaviour prior to contracting a dementing illness, and aggression may be a perpetuation of habitual ways of responding to situations. O'Leary *et al.* (2005) found that people with dementia who had a history of conduct disorder were more likely to be aggressive towards their partners. However, other research has not found a clear link between pre-morbid personality and aggressive behaviour in people with dementia (Kolnowski & Garr 1999, Low *et al.* 2002). Overall, while dementing illnesses can cause personality change, this may actually serve to reduce a person's tendency to behave aggressively.

Second, aggressive behaviour may occur as a consequence of the illness process. Traditional perspectives on dementia have tended to regard challenging behaviours as random expressions of neurological damage (Kitwood 1997). More recent research has highlighted links between aggressive behaviour and other psychological symptoms of dementia. Correlations have been found between aggressive behaviour and delusional thinking (Gormley *et al.* 1998, Eustace *et al.* 2001), and with symptoms of depression (Lyketsos *et al.* 1999, Talerico *et al.* 2002). Ballard *et al.* (2001) have suggested lowered levels of 5-HT and acetylcholine as mediating aggressive behaviour in people with dementia.

Third, aggressive behaviour may occur for psychosocial reasons. Stokes (2000) adopts Kitwood's person-centred model of dementia (Kitwood 1997), and regards challenging behaviour as 'poorly communicated need'. This view holds that aggressive behaviour perpetrated by a person with dementia is purposive, and often underpinned by the need to remove a perceived threat. Research indicates that aggressive behaviour happens most often when the person is receiving intimate care (Keene *et al.* 1999), suggesting that the person misinterprets such care for a personal vio-

lation by the professional carer. This view is reinforced by studies involving observation of interactions between professionals and people with dementia during intimate care. These suggest that the approach adopted by the carer is a factor in whether the person with dementia responds aggressively. For example, Somboontanont *et al.* (2004) found that people with dementia who were being bathed were more likely to react aggressively if carers communicated negatively with them, invalidated their experience, were too hurried or disrespectful, or did not give verbal prompts before spraying water. Skovdahl *et al.* (2003) similarly found that carers who reported difficulties with aggressive behaviour focused on accomplishing the task in the shortest time, rather than on the process of interacting with the person. The notion that care staff can trigger aggression in people with dementia therefore has some support from research, and echoes findings with other groups of people with mental health problems. Duxbury (2002) reported that patients of an acute inpatient unit felt that the interpersonal style adopted by some nurses was a contributory factor in triggering aggressive incidents.

Reactions of professional carers to aggressive behaviour

Increased attention has focused in recent years on aggression and violence by users of healthcare services against professionals. The psychological and physical impact of such incidents on victims has been acknowledged, and the notion that aggression against care staff is unacceptable has been reinforced by government initiatives including the NHS Zero Tolerance to Violence campaign. However, such initiatives begin with the assumption that aggression on the part of service users is deliberate and unprovoked, which, as suggested above, is rarely the case with people with dementia.

The reactive and seemingly non-intentional nature of aggressive behaviour by people with dementia, coupled with the likelihood that such aggression is only rarely physically injurious to the victim, has led to the view that it is a relatively trivial phenomenon that should be accepted by professional carers as 'part of the job' (Gates *et al.* 1999). This perspective is not, however, always shared by those professional carers who are victims of aggressive behaviour. Research suggests that professionals are ambivalent about the intentionality of acts of aggression carried out by people with dementia. Some are prepared to accept aggressive behaviour as non-intentional, while others hold the view that the person acts deliberately (Oser 2000, Astrom *et al.* 2004). However, no clear link has been found between the ways that professionals attribute aggressive behaviour and their willingness to help aggressive people

with dementia. Todd & Watts (2005) found that professionals who believed that people with dementia were being deliberately aggressive were no less likely to express positive views towards helping those people than professionals who believed that aggression was unintentional.

A more significant finding is that professional carers experience considerable stress, negative feelings and burn-out as a result of being the victims of aggressive behaviour (Gates *et al.* 1999, Oser 2000, Rodney 2000, Evers *et al.* 2002, Astrom *et al.* 2004). Perceived threat leads to raised stress, and persistent physical aggression results in emotional exhaustion. Overall, the view that aggressive behaviour is a relatively minor inconvenience of the job is not shared by those who are recipients of that aggression.

The negative reactions of professional carers to assault may also lead to the perpetuation of aggressive behaviour in those they care for. Gates *et al.* (2003) point out that the emotional toll on caregivers of repeated assaults will have an impact on the care they give, and may lead them to respond to aggressive behaviour by being aggressive or abusive themselves. It appears that in some cases care staff can get into a vicious circle of triggering aggression by responding in negative ways if they are the victims of aggressive behaviour. The finding mentioned above that apparently similar care settings can experience widely differing incidences of aggressive incidents may reflect different ways that staff interact with residents, and respond to aggression (Gates *et al.* 2003).

Conceptual approaches to the management of aggressive behaviour

A number of conceptual approaches to the management of aggressive behaviour by people with dementia can be identified. These approaches can be used in conjunction with each other, but they tend to derive from different philosophical bases, leading to the question of which approach should be preferred in any situation. Research evidence for the effectiveness for each approach will be considered where available.

The pharmacological/physical approach

This approach derives from the 'standard paradigm' of dementia care (Kitwood 1997), which views challenging behaviour as the more or less random consequence of neurological damage, and considers that the best response to such behaviour is to minimize its occurrence and effects by using tranquilizing drugs and/or physical restraints. Anti-psychotic drugs have long been used with people with dementia who exhibit aggressive behaviour, both to reduce psychological symptoms that may lead to

aggression, such as delusional thinking, and to sedate them, thereby reducing their aggressiveness. The research evidence for this approach is, however, mixed. Some studies have found evidence for the effectiveness of pharmacological interventions in reducing aggressive behaviour (Raskind 1999, Mintzer 2001, Brodaty & Low 2003, Lawlor 2004), while other studies have found limited positive effects of neuroleptic drugs (Schneider *et al.* 1990, Lee *et al.* 2004, Sink *et al.* 2005). Side effects are a major concern when using these drugs with people with dementia. These can particularly affect people who have Dementia with Lewy Bodies (Barber *et al.* 2001), but for all, anti-psychotic drugs have been linked with quickened cognitive decline (McShane *et al.* 1997), and recently with increased risk of adverse cerebrovascular events (Committee on Safety of Medicines 2004). Such problems have led the Royal College of Psychiatrists (2004) to propose that:

... non-pharmacological management approaches should always be considered first for people with dementia.

While psychoactive drugs may reduce aggression by dispelling psychiatric symptoms such as delusional thinking or depression, in many cases drugs are used principally for their sedative properties. The pharmacological approach to aggression management therefore focuses on using medication to minimize the occurrence of unwanted behaviour, rather than assisting people with dementia to interact with others, or to get their needs met, in more positive ways.

Elimination of aggressive behaviour may also be achieved by purely physical means. Physical restraint of people with dementia may be achieved by holding the person's arms and body during personal care activities, through the use of mechanical devices such as restraining chairs or cot sides, or by employing control and restraint techniques to prevent the individual from attacking another person.

There is little literature on the use of physical restraint with people with dementia who display aggressive behaviour. It seems highly likely that ad hoc holding of limbs or body to facilitate personal care is common (Kirkevold *et al.* 2004). Shaw (2004) revealed that staff in one nursing home in the United States adopted a practice they called 'bulldozing', in which two or more care staff would team up to forcibly carry out personal care with uncooperative residents. It also seems likely that mechanical restraints are still employed with people with dementia, despite reports that have highlighted the potential abusive nature of such practices (Commission for Health Improvement 2000, 2003). Existing literature suggests, however, that mechanical restraints are most commonly used with those who are inclined to fall, or have other physical problems, rather

than as a means of managing aggression (Retsas 1998, Karlsson *et al.* 2000). Finally, little has been written about the use of control and restraint strategies with people with dementia, other than a general warning to take physical decline into consideration if restraining older people (NIMHE 2004). The area of physical restraint as a means of managing aggression in people with dementia is undoubtedly grey and unclear, with little literature to guide practitioners in the use of such strategies, and the possibility of them being used in an abusive way is therefore heightened.

The environment management approach

This approach derives from two related assumptions. First, it is suggested that people with dementia are particularly sensitive to stress-provoking factors within their physical environment, and may react to these factors with challenging behaviour such as aggression. Second, it is held that providing an environment that takes account of the cognitive disabilities of dementia allows some behaviours, for example, wandering, to be reframed as non-challenging, with a consequent reduction of aggression from individuals prevented from walking around their living space. Stokes (2000) observes that aggressive behaviour in people with dementia, being almost invariably reactive, cannot be viewed outside the context of the person's physical or social environment.

The literature has developed regarding the optimum living environment for people with dementia who may be prone to challenging behaviours (Marshall 2000, Stokes 2000), embracing fundamental principles such as homely furnishings and decoration; colour and lighting that aids perception; minimization of stress-provoking background noise; space for people to not feel overwhelmed by others, and safe and stimulating areas for the person to walk about in. Calkins (2002) discusses ways of reducing aggressive behaviour during personal care activities by providing a relaxing and reassuring environment within the bathroom, by downplaying institutional features and highlighting home-like features; minimizing loud echoing noises that can be highly stressful to a person with dementia; accompanying the activity with music liked by the person, and providing pleasant smells.

While much of current thinking about the physical environment appears to have common sense validity, there are no specific research studies for the effectiveness of these measures in reducing aggressive behaviour among people with dementia. There are also of course very many care areas for people with dementia that are not built to the specifications recommended in the literature, and converting some environments would be highly costly.

The behaviour modification approach

It has been suggested that challenging behaviours in people with dementia may have their genesis in operant conditioning. In technical terms, variable interval, intermittent reinforcement schedules produce behaviour that is most resistant to extinction. This means that inconsistent responses by staff to aggressive behaviour may lead to that behaviour becoming entrenched and resistant to intervention (Ballard *et al.* 2001). The behaviour modification model holds that if people with dementia can learn aggressive behaviour, then learning theory principles can be adopted to extinguish such behaviour. Writers such as Wells & Wells (1997) suggest that analysis of the antecedents and consequences of aggressive behaviour can lead to staff devising interventions that will deny positive reinforcement to such behaviour, and if these interventions are implemented consistently, that behaviour will be reduced or eliminated.

Other authors dispute that behaviour modification is feasible or appropriate for people with dementia. For example, Stokes (2000) opines that the research evidence for the effectiveness of behaviour modification techniques in altering the behaviour of people with dementia is sparse, and also holds that the underlying philosophy of behaviour modification, that behaviour can be changed by selectively manipulating reinforcers, is inimical to person-centred values of respect and understanding of the emotional world of the person. Behaviour modification consequently remains the most controversial, and least used strategy for managing aggressive behaviour in people with dementia.

The person-centred approach

The person-centred approach focuses on attempting to understand the poorly communicated need being expressed by the aggressive person, and finding individualized ways of meeting that need (Stokes 2000). Such strategies may embrace individualized care plans for assisting residents to complete activities of daily living without provoking aggressive responses. Another focus is the use of individual or group activities to relieve boredom, dispel energy and engender a sense of well-being in participants. Research evidence for the effectiveness of the person-centred approach to managing aggressive behaviour is derived partly from evaluative studies of particular psychosocial therapeutic techniques, and partly from studies of training programmes that teach person-centred principles to professional carers. Such programmes aim to increase staff understanding of the causes of aggressive behaviour, and their skills in managing such behaviour by responding more individually and creatively to the person's needs (Turner

2005). A number of case studies have also appeared in the literature describing creative strategies for managing aggressive behaviour in individual residents, derived from an understanding of how the person's life history influences present ways of reacting to situations (e.g. Innes 1996, Stokes 1996).

The evidence for the effectiveness of specific individual or group activities has been reviewed by Turner (2005) and Verkaik *et al.* (2005). Interventions discussed include validation, multi-sensory stimulation, psychomotor therapy (embracing sports and physical games) and aromatherapy. Both reviews conclude that the methodological quality of the literature is rarely high, and that the few rigorous studies offer limited evidence for the effectiveness of these interventions for reducing challenging behaviour such as aggression.

A small number of evaluative studies of training programmes that have reduction of aggressive behaviour as a direct independent variable have been carried out. These studies are compromised by small sample sizes, non-experimental designs, short follow-up periods and non-control of extraneous variables, such as medication management. They provide tentative evidence for the effectiveness of giving care staff training in person-centred care principles and interaction skills for reducing aggressive behaviour (Maxfield *et al.* 1996, Clark *et al.* 1998, Wilkinson 1999, Gormley *et al.* 2001, De Young *et al.* 2002, Skovdahl *et al.* 2003, Savage *et al.* 2004, Gates *et al.* 2005). Interventions held to be useful include: getting to know the person well and treating residents with respect and appreciation; appropriate communication techniques, including validation of the person's utterances; behavioural analysis of aggressive incidents; avoidance or modification of individual precipitating factors; and distraction, including use of music during caregiving activities.

The evidence for the effectiveness of person-centred care principles is further compromised by practical problems with implementing such principles in residential care settings. Training programmes have been criticized for being focused more on awareness raising than on equipping care staff with new skills (James 2001). Changes in care regimes as a result of training have proved difficult to sustain (Moniz-Cook *et al.* 1998, Lintern *et al.* 2000). Turner (2005) suggests that this may be due to high staff turnover, or to the desire of staff to eliminate challenging behaviour altogether, and their discouragement and reversion to old ways when this does not happen following changes in patterns of care. Gates *et al.* (2005) found that a training programme only led to a reduction of aggression against care staff who had previously experienced few assaults, suggesting that some staff who are frequent recipients of aggres-

sion may be less open to considering new ways of interacting with residents.

Aggression management in practice

There is therefore a range of approaches to managing aggressive behaviour in people with dementia, albeit largely implicit and not clearly defined. These approaches derive from broadly differing conceptualizations of the nature and management of aggressive behaviour, but while their philosophical and ethical underpinnings differ, they are not mutually exclusive and can be used in combination. However, there is limited research evidence for the effectiveness of these approaches, and no clear evidence of the efficacy of any one approach means that application is difficult.

There are also potential practical and sometimes ethical problems with each conceptualization. The pharmacological/physical approach used in an unthinking way can deny the personhood of the individual, and can leave the person prone to damaging side effects, and even the risk of abuse. The environmental management approach may be difficult to implement in some care settings. The behaviour modification approach again may compromise personhood, and the person-centred approach, while ethically sound and supported by current policy, may be hard to implement and sustain in care settings with high staff turnover (Sheard 2004). While the latter approach has much to commend it on ethical grounds, as it implies high-quality nursing care, it is difficult on the basis of current research evidence to make a clear recommendation as to whether it or another approach should be adopted as best practice. Practitioners may be best advised to adopt a multifactorial strategy to both understanding and intervening with aggressive behaviour, basing their approach on the particular circumstances of each individual (Turner 2005).

Along with the difficulty in making clear recommendations for practice, there is a dearth of information as to which strategies are actually adopted at present by professional carers. To date, few studies have directly examined which approaches to the management of aggressive behaviour are most commonly used in practice. Foley *et al.* (2003) interviewed staff in nursing homes in the United States and found that they used a range of psychosocial methods, and physical restraints only as a last resort. By contrast, Kirkevold *et al.* (2004) and Shaw (2004) found that physical restraints were commonly used in residential care settings.

Anecdotal evidence suggests that tranquilizing drugs are still frequently employed to manage aggressive behaviour. This impression is supported by studies that indicate excessive prescription of anti-psychotic drugs within care facilities for people with dementia (Furniss *et al.* 1998, Bullock

2004), but there is little direct information as to whether these are actually being used as the treatment of first resort, or what, if any, alternative management strategies are being adopted. Further research into the actual aggression management strategies adopted in care facilities for this client group may indeed highlight areas of good practice that have not been uncovered by existing studies. There is a need for large-scale, well-controlled studies that examine the current range of interventions, including comparative studies, in order to give staff clearer guidance in this difficult area of care.

Conclusion

This paper has considered the phenomenon of aggressive behaviour perpetrated by people with dementia in residential care settings. The emotional impact of assaults on nurses and other professionals has been highlighted, and differing perspectives on the causation of aggressive behaviour have been considered. Management strategies derived from these perspectives have been reviewed. Our conclusion is that while certain strategies appear to reflect good and common sense practice, there is no clear research evidence for the general effectiveness of any one management approach, and each approach has drawbacks of a practical or ethical nature. There is also little empirical information about how professional carers actually manage aggressive behaviour in practice.

Nurses should consider the full range of strategies open to them for reducing incidences of aggressive behaviour, but the question remains of which approach should be tried first. The lack of direct evidence as to which strategies are actually adopted in practice means that we cannot say for sure which approach predominates in residential care settings, but we may surmise that the pharmacological/physical approach still dominates, despite the equivocal evidence for its effectiveness, the potentially damaging side effects of many current drugs, and the possibility of physical restraint leading to abuse. Current opinion inclines to the view that this situation should be reversed, and that the person-centred approach should be adopted as the strategy of choice, with physical and pharmacological methods used only as a last resort (Stokes 2000, Royal College of Psychiatrists 2004). Not only are person-centred approaches held to be ethical and free of side effects, but also they acknowledge that aggressive behaviour by people with dementia is commonly a reaction to events in the person's environment, including the sometimes untherapeutic approach adopted by professional carers. At the same time, research to date has not clearly established that person-centred strategies are superior to other ways of managing aggression and, in the absence of clear evidence-based guid-

ance as to its management, aggression is still a frequent occurrence in residential care settings.

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A survey of staff attitudes and responses to people with dementia who are aggressive in residential care settings

D. PULSFORD¹ MPhil BA(HON) RMN, J. A. DUXBURY² PhD MA BSc RMN RGN & M. HADI³ BSc MSc

¹Senior Lecturer in Mental Health, ²Reader in Mental Health Nursing, and ³Research Assistant, School of Nursing & Caring Sciences, University of Central Lancashire, Preston, Lancashire, UK

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Correspondence:

J. A. Duxbury
School of Nursing & Caring Sciences
University of Central Lancashire
Preston
Lancashire
PR1 2HE
UK

E-mail: jduxbury@uclan.ac.uk

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Accessible summary

- An exploration of the attitudes of staff in care homes and the strategies they use to manage aggression is relatively under researched in the UK.
- Given the lack of research in this area the development of the Management of Aggression in People with Dementia Attitude Questionnaire was required.
- It is clear that despite some concerns about practices in older people's settings, the findings of this study highlighted a positive emphasis upon person-centred approaches to care in both prevention and management of aggression. This was reflected in staff attitudes.

Abstract

Aggression is reportedly common among older people with dementia in residential care. The attitudes of staff in care homes and strategies they use are under researched. Theoretical models that may be used to both understand and respond to such behaviour exist. They are the standard and person-centred paradigms. The aim of this study was to explore the views of nursing staff about aggressive behaviour in people with dementia and strategies used in practice. A survey of the attitudes of staff in six dementia care units using the Management of Aggression in People with Dementia Attitude Questionnaire was conducted including an audit of aggressive incidents using the Staff Observation Aggression Scale – Revised over a 3-month period. Staff expressed views reflective of a person-centred as opposed to standard paradigm. They viewed aggressive behaviour by people with dementia as deriving from the environment, situation or interactions with others. Participants strongly supported interpersonal means of responding to aggression, the moderate use of medication, and were largely opposed to physical restraint. Aggressive incidents were managed using less intrusive strategies such as distraction and de-escalation. Responses to aggressive behaviour, while pragmatic, were largely underpinned by a person-centred ethic as reflected in the attitudes expressed by staff.

Introduction

In the UK, around one-third of older people with dementia live in residential care settings, representing over 200 000

individuals, and over 60% of UK care home residents have dementia (Alzheimer's Society 2009). Challenging behaviours such as verbal and physical aggression are common among people with dementia in residential care (Ballard *et al.* 2001). While most aggressive behaviour by people with dementia is relatively non-injurious (Astrom *et al.* 2004), more serious incidents can occur. It is

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suggested that being the target of aggression can lead to increased stress and burn-out among nurses and care staff (Rodney 2000, Astrom *et al.* 2004).

A range of strategies is available to UK nurses and care home staff to respond to aggressive incidents by residents with dementia. These include interpersonal approaches such as de-escalation or distraction. Alternatively, staff may utilize more controlling responses including medication, isolating the aggressive person and physical restraint, defined as staff manually restraining a resident in some way. The use of mechanical restraint with people with dementia, involving straps, confining clothing or confining chairs, is generally regarded as abusive practice in the UK (Commission for Health Improvement 2000).

Although there is no clear evidence that there is an absolute way to respond to aggressive behaviour (Pulsford & Duxbury 2006), guidelines have been produced in both the UK (National Institute of Clinical Excellence 2006) and the USA (Dettmore *et al.* 2009) advocating interpersonal means of responding to aggressive behaviour by people with dementia as the approach of choice. It is strongly recommended that 'controlling' means should only be used as a last resort. It is, however, unclear what attitudes are held by nurses and other care staff in UK care homes towards aggressive behaviour by people with dementia, and what strategies are used in practice to respond to such behaviour. This paper reports on the first published survey carried out in the UK into this aspect of dementia care.

Background

Duxbury (2002) argues that care staff's approaches to aggression are likely to be governed by their attitudes regarding the nature of aggressive behaviour. The dichotomy between 'controlling' and 'interpersonal' means of responding to aggressive behaviour can be seen as reflecting differing philosophies of dementia care. Kitwood (1997) contrasted the 'standard paradigm' of dementia care with the 'person-centred' paradigm. The 'standard paradigm' he suggests focuses on the neurological and neuro-psychiatric aspects of dementia, holding that the way that dementia is manifested in the person is predominantly a function of neurological disease. The 'person-centred' paradigm regards neurological disease as being only one of several factors that influence the manifestation of dementia in a person, with the person's biography and personality, physical and mental health, and interactions with others being equally important. Using the standard paradigm it can be argued that challenging behaviours such as aggression are essentially random expressions of the neurological damage caused by the disease processes that lead to dementia, or reflect under-

lying personality traits. The assumption is that there is little that professional carers can do other than to control the person's behaviour with tranquilizing medication or restraint. The person-centred paradigm, by contrast, sees meaning in the person's behaviour, regarding expressions of aggression as 'poorly communicated need' (Stokes 2000). Professional carers should try to interpret the person's behaviour in terms of the underlying need and look for ways of meeting that need through the use of interpersonal interaction. The extent to which care home staff embrace the standard paradigm or person-centred philosophies can therefore influence their choice of response to aggressive behaviour.

There has to date been little research worldwide into these matters. Nakahira *et al.* (2008) surveyed staff attitudes about aggressive behaviour by people with dementia in nursing homes in Japan. Staff completed the Attitudes Towards Aggression Scale (Jansen *et al.* 2005). A range of views were expressed. Older, more experienced and better educated staff reported more positive attitudes (in the sense of embracing a more person-centred approach). These staff were less likely to report using physical restraint than those with negative attitudes, although interestingly staff with more positive attitudes were more likely to report using medication as a response to aggression. Almvik *et al.* (2006) conducted an audit of aggressive incidents and how they were resolved in residential care facilities in Norway, using the Staff Observation Aggression Scale – Revised (SOAS-R: Nijman *et al.* 1999). Talking to residents was the response in 63.5% of incidents, although it was the sole response in only 20% of incidents. 'Seclusion' of the aggressive resident was resorted to in 30.2% of incidents and 'holding with force' in 21.7%. Oral medication was administered in 21.7% of incidents.

Other studies have gathered qualitative data from nurses and care home staff, finding a range of views about the nature of aggressive behaviour and how to respond to it. In a US study, Foley *et al.* (2003) asked nurses in residential dementia care units to identify incidents of aggressive behaviour that they regarded as having been responded to successfully compared with incidents that were not well managed, and the strategies used in those incidents. Respondents felt that person-centred strategies led to greater success than the use of medication, and physical restraint was used as a last resort. Manderson & Schofield (2005) published a brief report of a wide-ranging series of interviews with nurses and care staff in New Zealand, hinting at a broadly person-centred approach to aggression management. By contrast, MacDonald (2007) in the UK asked care assistants about their conceptualization of aggressive behaviour by residents, finding that his respondents had a nihilistic view, believing such behaviour to be

an inevitable consequence of dementia and feeling powerless to manage it in a positive way.

The literature therefore indicates that while care home staff hold a range of attitudes and adopt a mix of aggression management strategies, attitudes reflecting the standard paradigm are often expressed and controlling approaches are commonly used. It has been suggested that aggression management in residential care in the UK involves overuse of controlling strategies such as tranquilizing medication (All Party Parliamentary Group on Dementia 2008). This paper aims to add to the literature by reporting on a survey of the attitudes of nurses and other staff in a sample of UK care homes regarding the causes of, and best ways of responding to aggressive behaviour among residents with dementia. Additionally, the results of an audit of aggressive incidents are presented, to offer data on the ways that aggressive incidents were conceptualized and responded to in practice.

Aims

- To explore the views of nurses, and care staff as to the causes of, and most effective ways of responding to aggressive behaviour by older people with dementia in residential care.
- To explore the strategies used in practice to respond to such behaviour in residential settings.

Method

Design

The study used a quantitative approach using a survey methodology. This comprised:

- A survey of the attitudes of staff using a specially constructed instrument, the Management of Aggression in People with Dementia Attitude Questionnaire (MAPDAQ).
- An audit of aggressive incidents to ascertain how aggression is responded to in practice, using the SOAS-R (Nijman *et al.* 1999).

Data collection

Settings and participants

The study was carried out in four nursing homes in the North West of England that were owned by the same national company. The homes included a total of six dementia care units, ranging in size from 15 to 30 beds.

All nursing and care staff from the participating units were invited to complete the MAPDAQ attitude question-

naire and to complete SOAS-R incident forms for any incidents of aggressive behaviour in which they were involved over a 3-month period.

Research instruments

The MAPDAQ attitude questionnaire was developed out of an existing instrument, the Management of Aggression and Violence Attitude Scale (MAVAS: Duxbury 2003). This is a scale used previously in acute inpatient settings (Duxbury 2002, Duxbury & Whittington 2005, Hahn *et al.* 2006, Duxbury *et al.* 2008). The MAVAS was adapted for use in care homes for people with dementia; the adaptation being informed by discussions with an expert group, the Higher Education for Dementia Network (<http://www.fordementia.org.uk/highered.htm>) Using the original MAVAS statements as a basis for discussion, the network were asked to comment on the use and appropriateness of the language, terminology and factors identified within the tool if applied to an older people's setting. This resulted in some changes being required. For example the impact of managing a patient's personal care or their experience of pain is known to be a particular trigger for aggression in dementia care units. Statements to this effect were therefore necessary. The use of the word dementia was also specifically used in many statements. The resulting MAPDAQ instrument contained 20 items, which asked respondents to give their views on possible causative factors for aggressive behaviour, and on how they felt that aggressive incidents should be responded to. Participants gave their views on each statement on a visual analogue scale, by marking a 100-mm straight line, the ends of which represent extremes of possible response (Howe 1995). The anchors at the extremes of the MAPDAQ are 'strongly agree' (given a value of 0) and 'strongly disagree' (given a value of 100). A low score therefore indicates agreement with a statement.

The MAPDAQ was subjected to psychometric testing. Test-retest reliability was estimated to be 0.817 using Pearson's *r* coefficient, indicating good reliability. Factor analysis revealed two main factors, accounting for all but one item, which was excluded from the final version. These factors were interpreted as firstly a person-centred perspective (eigenvalue 4.284) and secondly a standard paradigm perspective (eigenvalue 2.639), offering evidence for the construct validity of the instrument.

The SOAS-R (Nijman *et al.* 1999) is a well-established tool for auditing aggressive incidents in a range of settings. It is completed by staff for any individual incident. It assesses incidents under five categories: provoking factors; the behaviour expressed; the target(s) of the aggressive behaviour; the consequences for the victims and the measures taken to resolve the incident. It is completed by staff

ticking items within each of the above categories that best reflect the nature of the incident. Minor modifications to SOAS-R were required for the present study. These were informed by discussions with senior practitioners within the care homes.

Data collection took place between March 2008 and April 2009. Meetings took place with staff on each participating unit to inform them of the study and to distribute MAPDAQ attitude questionnaires. Staff were encouraged to complete these in their own time and return them by post to the investigators. A period of 3 months was identified at each unit for the prospective audit of aggressive incidents; a folder of SOAS-R incident forms was left at each unit for that purpose. Units were visited regularly by a member of the research team to collect completed forms.

Data analysis

The MAPDAQ attitude questionnaire was analysed on a question-by-question basis using descriptive statistics. The SOAS-R incident forms were similarly analysed using descriptive statistics.

Ethical considerations

Ethical approval for the study was gained from a local research ethics committee, related R&D forums, the university's ethics committee, and the care home company's internal committee. Relatives of residents were written to before commencement of data collection and if they felt their family member would object to having research data collected about them, information about that resident was excluded from the study. Information sheets were circulated to all potential participants. Consent of staff regarding completing MAPDAQ and SOAS-R forms was accepted if staff completed and returned forms.

Staff completed MAPDAQ attitude questionnaires anonymously and residents were identified on SOAS-R incident forms by code letters only.

Results

Staff attitudes from MAPDAQ

A total of 36 staff members completed the MAPDAQ out of a possible 52, a response rate of 70%. Table 1 details the gender of respondents, and whether they were qualified nurses or unqualified care staff.

Overall findings are set out in Table 2.

Causation

The results suggest that staff were more inclined to subscribe to a person-centred than the standard paradigm. As

Table 1
Characteristics of MAPDAQ respondents ($n = 36$)

	Qualified nurse	Unqualified care staff
Female	12	14
Male	3	7
Total	15	21

MAPDAQ, the Management of Aggression in People with Dementia Attitude Questionnaire.

can be seen from the mean results in Table 2, they broadly felt that the causes of aggressive behaviour can be found in the immediate situation, or in the interaction of the person with others (statements 2, 16 & 19). Restrictive environments were also seen to be influential (statements 10 & 18). Interestingly, staff were ambivalent in their responses to statement 1: other people make people with dementia aggressive.

Management

Staff more commonly disagreed with statement 15: aggression could be handled more effectively in this home. They strongly supported interpersonal and non-physical methods of responding to aggressive behaviour (statements 9, 13 and 17). In contrast, staff were less inclined to express views that were reflective of a standard paradigm perspective. They tended to disagree that the causes of aggressive behaviour could be found in personality factors (statement 3), though they supported (not strongly) statement 4: people with dementia are aggressive because of the illness that they have. They disagreed that people with dementia should control their feelings (statement 5).

Staff supported the use of medication as a way of responding to aggressive behaviour, but not strongly (statements 8, 12 and 16). However, they were strongly opposed to the use of isolation and restraint as aggression management strategies (statements 6, 7 and 11).

Aggressive incidents; SOAS-R results

The results of the 3-month prospective audit of aggressive incidents are presented in Table 3.

Seventy-nine forms were completed in total. This included reported incidents involving 31 residents across the six dementia care units. This figure does not reflect the total number of aggressive incidents that happened in each unit during the data collection period. Some relatives felt that the resident to whom they were related would not wish to consent to taking part in the study, and consequently incidents involving those residents were excluded. Guidance on the Mental Capacity Act (2005) and research involving, or in relation to, a person lacking capacity, states that carers or nominated third parties (personal consultees)

Table 2
MAPDAQ results of care home staff ($n = 36$)

Person-centred perspective	Mean	Median	SD
Causes of aggressive behaviour			
2. If staff do not listen to residents with dementia, they may become aggressive	29	15	30
19. Residents with dementia may be aggressive because they don't understand what staff are trying to do for them	25	13	28
1. Other people make people with dementia aggressive	50	49	30
15. People with dementia may be aggressive because they are in pain	28	25	27
10. Restrictive environments can contribute towards aggression	22	10	26
18. If the physical environment were different, people with dementia would be less aggressive	35	49	27
Responding to aggressive behaviour: general views			
14. Aggression could be handled more effectively in this Home	58	64	31
Responding to aggressive behaviour: use of non-physical methods			
9. Talking to the person is an effective way of managing aggression	26	15	27
13. Improved relationships between staff and residents with dementia can reduce aggression	21	10	25
17. The use of distraction is helpful in managing aggression	25	14	28
Standard paradigm perspective	Mean	Median	SD
Causes of aggressive behaviour			
3. People with dementia are aggressive because that's their personality	69	73	26
4. People with dementia are aggressive because of the illness that they have	43	44	31
5. People with dementia should control their feelings	73	92	26
Responding to aggressive behaviour: use of medication			
8. Medication is a valuable approach for managing aggression	43	47	29
12. Alternatives to medication could be used more frequently in this Home	58	56	27
16. Prescribed medication should be used more frequently for aggressive behaviour	60	57	29
Responding to aggressive behaviour: use of isolation			
6. Staff should be able to isolate an aggressive resident in a separate room	58	73	36
Responding to aggressive behaviour: use of restraint			
7. People with dementia who are aggressive should be physically restrained for their own safety or the safety of others	61	75	36
11. Physical restraint is used more than necessary in this Home	87	94	17

Low scores indicate agreement with a statement; high scores indicate disagreement with that statement. MAPDAQ, the Management of Aggression in People with Dementia Attitude Questionnaire.

must be consulted and agree that the person would want to join an approved research project (Department of Health 2008).

Given the relatively small number of incidents reported, comparisons between individual units have not been made in this instance.

The most common identifiable cause of aggressive incidents was staff attempting to give personal care, followed by interaction with other residents, the person being denied something and general interaction with staff. Interestingly, staff reported that the greatest number of incidents had no apparent provocation. Physical assault occurred in 56.9% of incidents.

In 75.9% of incidents the target of aggression was a staff member(s). Fellow residents were the target in 31.6% of incidents (some incidents had more than one target). No consequences were reported in nearly half of occurrences, and the victim felt alarmed, upset or threatened in a quarter of incidents. Minor physical injury not requiring treatment was a consequence of another quarter of incidents and only one incident resulted in minor injury requiring treatment.

Staff reports of their responses to incidents were largely reflective of the attitudes expressed in the MAPDAQs.

Interpersonal or non-physical responses were made in the majority of incidents (65.4%), including talking to the resident, distracting the resident and reassuring the resident. In around a quarter of cases the resident was removed from the place of the incident. Physical restraint was used in nine incidents and medication on just one occasion.

Discussion

The results of our survey indicate that the staff in the participating dementia care units lean more towards a person-centred than a standard paradigm when considering the aggressive behaviour of residents. MAPDAQ responses suggest that staff view the causes of aggressive behaviour to be predominantly situational, the result of interactions with staff or caused by the environment of care. Aggressive behaviour is therefore largely seen by staff as an interpersonal phenomenon.

This is not dissimilar to the findings reported upon in the study by Nakahira *et al.* (2008) in Japan. In contrast, however, in a survey of staff in acute psychiatric inpatient units in the UK (Duxbury 2002, Duxbury & Whittington 2005), respondents tended to regard factors internal to the

Table 3
Staff Observation Aggression Scale – Revised (SOAS-R, adapted)

	No.	%
Incident provoked by:		
No apparent Provocation	27	34.2
Interaction with other resident(s)	12	15.2
Interaction with Visitor	2	2.5
General interaction with staff	5	6.3
Staff attempting to give personal care	20	25.3
Staff attempting to give medication	1	1.2
Resident denied something	7	8.8
Resident experiencing pain or discomfort	1	1.2
Resident's actual behaviour		
Verbal abuse	33	41.7
Verbal threat of physical aggression	11	13.9
Physical aggression towards a person(s)	45	56.9
Damage to property	1	1.2
Other (Resident grabbed visitor's bag)	1	1.2
Target of aggression		
Nothing/nobody	1	1.2
Property	2	2.5
Staff member	60	75.9
Other resident	25	31.6
Visitor	3	3.8
Self	0	0
Consequences for victim(s)		
None	35	44.3
Property damaged	1	1.2
Victim felt alarmed or upset	18	22.8
Victim felt threatened	4	5.1
Victim had clothing ripped	1	1.2
Physical injury not requiring treatment	19	24.1
Minor physical injury requiring treatment	1	1.2
Major physical injury requiring treatment	0	0
Measures taken		
None	4	5.1
Incident resolved by talking to resident	30	37.9
Incident resolved by distracting resident	16	20.2
Oral medication given	1	1.2
Medication given by injection	0	0
Resident physically restrained	9	11.4
Resident removed from place of incident	19	24.1
Other		
Resident given space	1	1.2
Reassurance given	6	7.5

Respondents may have ticked more than one response for each category

Total Number of forms: 79

Time of Incident: Night 18 Morning 21 Afternoon 36
Not stated 4

Gender of Resident: Male 45 Female 32 Not stated 2

Total number of residents that forms apply to: 31

aggressive person, such as personality or illness as more significant. This resulted in controlling management strategies such as medication, restraint and seclusion being used rather than interpersonal strategies such as de-escalation.

Respondents to the MAPDAQ showed considerable support for the use of interpersonal strategies for responding to aggression although there was some support for the use of medication. This was not overtly strong, however, and staff more commonly agreed that while valuable it should not be used more than at present. Staff were par-

ticularly opposed to isolating aggressive residents and to using physical restraint. This reflects advocated therapeutic principles of care in dementia care (Kitwood 1997, Stokes & Goudie 2002, National Institute of Clinical Excellence 2006).

Results from aggressive incidents recorded substantiated the views articulated by staff, although it is of note that a number of incidents were rated as having no apparent provocation. This may mean that staff regarded those incidents as deriving from internal factors including dementia, or that immediate triggers could not be identified. Where provoking factors were evident, these tended to be attributed to occasions of personal care, interactions with other residents or the person being denied something by staff. These factors have been identified as significant triggers for aggression in other studies (Almvik *et al.* 2006, Whall *et al.* 2008).

Physical aggression occurred in over 50% of incidents, possibly reflecting the fact that many care home residents have language impairments that prevent them from expressing themselves verbally. Unsurprisingly, staff were the target of the large majority of incidents, although a significant proportion of incidents were of resident-to-resident aggression, a phenomenon that is sometimes given less attention (Rosen *et al.* 2008).

Interpersonal responses were reported in SOAS-R returns for the majority of incidents, involving talking to residents, reassuring or distracting them. The most common 'controlling' strategy was for staff to remove the person from the scene of the incident. Physical restraint was recorded in 11% of incidents. Medication was given as a specific response to just one incident. This was interesting given that staff attitudes alluded to support for the use of medication. It would appear that concerns recently expressed in the UK regarding the overuse of medication in care homes (All Party Parliamentary Group on Dementia 2008) are not reflected in this study.

Despite the interpersonal approach adopted across the units it was generally accepted that controlling strategies may be warranted in some circumstances. Restraint was used more than medication. However overall, our results show much lower levels of controlling responses than the only other comparable study, that of Almvik *et al.* (2006), where high frequencies of seclusion, physical restraint and oral medication use were reported.

The study has a number of limitations. It was conducted in a small number of care homes, all owned by the same company, and may not be representative of all UK older people care settings. A limited number of staff completed the MAPDAQ attitude questionnaire, meaning that more detailed analysis of responses could not be carried out. It cannot be assumed that the audit of incidents using the

SOAS-R captured all incidents that occurred particularly as a number of residents were excluded from the study. Finally, resource limitations meant that some interesting questions could not be investigated. For example, it would have been instructive to audit medication use in the units and to interview residents themselves.

Conclusion

In conclusion, it is evident that staff in this study displayed a broadly person-centred approach to aggressive behaviour from residents, while recognizing that some aggression was difficult to understand in terms of situational factors, and that controlling approaches were needed in some cases. Our findings appear to contradict reports in the UK of overuse of controlling strategies such as tranquilizing medication, but we may question whether our findings are representative of the UK care sector as a whole. It may be that the homes we studied have a common ethos, aggression management policy and approach to staff training that is reflective of therapeutic communication, an approach that may not be pursued universally. Almvik *et al.* (2006) found that in Norway 'controlling' means of aggression management tended to be more commonly used in 'general geriatric wards' than in specialized dementia care units. This may also be the case in the UK. With little evidence to make useful comparisons, more research is needed into this aspect of dementia care. At the same time, our finding that interpersonal means of responding to aggressive behaviour is, in most cases, the strategy of choice for staff in these care homes reflects a philosophy of care advocated across the spectrum of dementia care by leading experts and is a positive outcome (Stokes & Goudie 2002, All Party Parliamentary Group on Dementia 2008).

Person-centred approaches to aggressive behaviour from older people with dementia are feasible and a preferred option in residential care settings despite concerns to the contrary. Given the need for greater work in this area, the MAPDAQ and the SOAS-R are valuable tools for exploring staff views and approaches to aggressive behaviour with this client group.

Acknowledgments

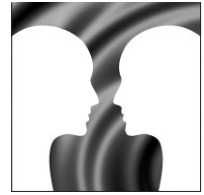
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Staff and relatives' perspectives on the aggressive behaviour of older people with dementia in residential care: a qualitative study

J. DUXBURY¹ PhD MA BSC RMN, D. PULSFORD² MPhil BA (HON) RMN, M. HADI³ MSc BSc & S. SYKES⁴ MSc BSc RMN RNT

¹Professor of Mental Health Nursing, ²Senior Lecturer Mental Health, ³Research Assistant, and ⁴Senior Lecturer Mental Health, Centre for Mental Health and Wellbeing, School of Health, University of Central Lancashire, Preston, Lancashire PR1 2HE, UK

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Correspondence:

J. Duxbury
School of Health
University of Central Lancashire
Brook Building 435
Preston
Lancashire PR1 2HE
UK
E-mail: jduxbury@uclan.ac.uk

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Accessible summary

- Staff and relative perspectives on patient aggression in dementia care units are seriously under researched in the UK.
- We interviewed a number of nursing staff and relatives in four UK care homes in the North West of England.
- Using a combined approach of one-to-one interviews (for staff) and focus groups (for relatives) we explored their views as to the reasons for and ways of responding to aggressive behaviour.
- Using thematic analysis we found similar results from both staff and relatives and as such their views were categorized into two broad areas: causation and management.
- The results indicated that staff in the participating units embraced a person-centred approach to aggression management. They predominantly respond to aggressive incidents with interpersonal strategies, such as distraction as opposed to medication or restraint.
- Relatives were clear in their perceptions of aggression as an interpersonal challenge, which is compounded or mediated by the illness of dementia. Consequently they were positive in their views of staff using non-coercive interventions.

Abstract

Staff and relative perspectives on patient aggression in dementia care units are seriously under researched in the UK. Any work that has been conducted has relied upon quantitative studies. Qualitative research on aggression management in older peoples services are rare. In-depth views that can offer insights into causation and management strategies are therefore under represented in the literature. In order to investigate this issue further we interviewed a number of nursing staff and relatives in four UK care homes in the North West of England. Using a combined approach of one-to-one interviews (for staff) and focus groups (for relatives) we explored their views as to the reasons for and ways of responding to aggressive behaviour. This was part of a larger study reported upon elsewhere. Using thematic analysis we found similar results from both staff and relatives and as such their views were categorized into two broad areas: causation and management. In regards to causation we noted three sub-themes; internal, external and interpersonal factors which are further subdivided in the paper and for management two broad categories: the compassionate approach and 'don't go in strong'. The results indicated that staff in the participating units embraced a

person-centred approach to aggression management. They predominantly respond to aggressive incidents with interpersonal strategies, such as distraction as opposed to medication or restraint. Overall they adopt a person centred approach to patient care. Relatives were clear in their perceptions of aggression as an interpersonal challenge, which is compounded or mediated by the illness of dementia. Consequently they were positive in their views of staff using non-coercive interventions. While the results of this and our earlier study are promising suggesting a less invasive approach to this aspect of dementia care, given the limitations of a small sample, more research of a similar nature is warranted. Findings from multidimensional studies can then provide a sounder basis for health and social care education, and person centred informed practice to reduce the incidence of aggression through preventative strategies.

Introduction

Over 200 000 people with dementia in the UK live in residential care settings (Alzheimer's Society 2009) and up to 86% display behavioural and psychological symptoms of dementia, including verbal and physical aggression (Ballard *et al.* 2001). Despite this there has been little research in the UK to date into the management of aggressive behaviour in UK care homes. The limited work that has been done has focused upon quantitative studies and more in-depth work to gain detailed perceptions and insights on the nature of the problem is lacking.

In order to explore this issue we carried out a study to investigate the management of aggressive behaviour in a number of UK care homes in the North West of England using a pluralistic design. The attitudes of nurses and care staff in a sample of dementia care units were surveyed to ascertain their views as to the causes and best ways of responding to aggressive behaviour. An audit of aggressive incidents in the participating care homes was also carried out to determine how such incidents are managed in practice (Pulsford *et al.* 2011). The results indicated that staff in the participating units embraced a person-centred approach to aggression management more commonly one reflecting the standard paradigm. In essence they predominantly respond to aggressive incidents with interpersonal strategies, using 'controlling approaches' such as medication or restraint as a last resort.

To enrich and add meaning to these findings, we have since gathered additional qualitative data to ascertain staff and relatives perspectives on aggressive behaviour by residents, by interviewing a representative sample of staff, and carrying out focus groups with relatives of residents in this study. This involved interviewing a representative sample of staff from the care homes surveyed and carrying out a number of focus groups with relatives in the participating care homes. The results of this qualitative phase are the focus of the current paper.

Background literature

When exploring aspects of aggression in healthcare settings it is important to define the nature of the problem. However, there are a number of definitions in the literature and defining aggression and violence is not easy given the lack of consistency in the terms used (Child & Mentis 2010). Rippon (2000) compared definitions from the literature and concluded that a number of factors were constant. They included the intent of the aggressor, the cognitive process and behaviour, which results in physical, psychological and/or emotional harm. Given the complexities of aggression and violence and the different settings in which it can occur, applying defined parameters is not so easy particularly in older peoples settings. Therefore, for the purpose of this study aggression is defined as 'any verbal, non-verbal or physical behaviour that threatens or is harmful to others or their property' (Morrison 1990). In this way we are not drawn into debates about intent or cognitive ability.

Search strategy

MEDLINE, CINAHL, Psych Info, EMBASE, and British Nursing Index were searched using the search terms aggression, violence, older people, care and residential homes, dementia and qualitative studies. When doing our background review we focused upon literature in older peoples mental health services and so used terms to reflect the nursing and clinical focus of the work and incorporated studies dating back to 1990. This search was supplemented with hand searches of leading mental health journals and by following up references within relevant papers.

Of all the behavioural and psychological symptoms of dementia, aggressive behaviour is perhaps the most demanding for families and professional carers (Rodney 2000). Both may be the recipients of threats and insults and at risk of injury from people whom they are trying to help.

It can contribute to the breakdown of caring arrangements within families and stress and burnout among professionals (Rodney 2000, Astrom *et al.* 2004). For example, aggressive behaviour is reported to be common when dealing with patients with dementia (Almvik *et al.* 2006).

Aligned to the nature and experience of aggression and violence are varied theories on causation. A resulting set of literature has emerged over the last 15–20 years that examines theoretical models on healthcare and clinical aggression. Nijman (2002) introduced a model that explored the multidimensional nature of aggression in specified settings of health care. This was later developed by Duxbury (2002, Duxbury & Whittington 2005) who explored the impact of internal, external and situational factors in determining chosen methods to manage the problem. This then resulted in the development of a scale that measured related staff and patient attitudes: the Management of Aggression and Violence Attitude Scale (MAVAS) (Duxbury 2003).

Fundamental principles that underpin good practice in dementia care, however, do exist, and these can be applied to the management of aggressive behaviour in residential care settings. Kitwood (1997) for example, talks of two conceptual frameworks that can underpin dementia care. First, there is the more traditional ‘standard paradigm’, which holds that behavioural and psychological symptoms are essentially random expressions of the neurological damage that dementing illness has caused, and that should therefore be controlled by the use of psychoactive drugs and physical restraints. In contrast, there is the increasingly advocated the ‘person-centred paradigm’, in which aggressive behaviours are regarded as ‘attempts at communication related to need’ and as such should be responded to by attempts to understand and respond to therapeutically any underlying need being expressed by the person (Stokes 2000). Such strategies are more likely to be social or psychological rather than medical or physical. Kitwood’s model shares some commonalities with Duxbury’s work in that there is a move to understand both the context of and relationships within a care environment that impact upon both causation and the management of aggression. For example whether priorities are person centred (interpersonal/situational) or from a standard paradigm (more biomedical and internally driven).

While much of the research to date has focused upon adult care in inpatient settings, there is a growing interest in the care of older people and what leads to aggressive behaviour in this setting. While much of the literature to date reflects a focus upon quantitative research, some studies have gathered qualitative data from nurses and care home staff worldwide regarding aspects of their experience of aggressive behaviour, finding a range of views about the nature of aggressive behaviour and how to respond to it.

Gates *et al.* (1999) in USA questioned care assistants and nursing directors about their reactions to being targets of aggressive behaviour, and the support (or lack of it) they received when victims of aggression. In another US study, Foley *et al.* (2003) asked nurses in residential dementia care units to identify incidents of challenging behaviour, predominantly involving aggression, that they regarded as having been responded to successfully compared with incidents that were not successfully managed, and the strategies used in those incidents. Respondents felt that person-centred strategies led to greater success than the use of medication, and physical restraint was used as a last resort. Manderson & Schofield (2005) published a brief report of a wide-ranging series of interviews with nurses and care staff in New Zealand, hinting at a broadly person-centred approach to aggression management. MacDonald (2007) in the UK asked care assistants about their conceptualization of aggressive behaviour by residents, finding by contrast that his respondents had a nihilistic view of aggressive behaviour, believing it to be an inevitable consequence of dementia and feeling powerless to manage it in a positive way (therefore embracing the standard paradigm perspective). Isaakson *et al.* (2008) in Sweden found a range of conceptualizations of aggressive behaviour among a sample of female care assistants, concluding that aggressive behaviour is ‘in the eye of the beholder’, and Rosen *et al.* (2008) in USA found that care home staff used a wide range of strategies for resolving resident-to-resident aggression, embracing both interpersonal and controlling approaches. Our study revisits these questions with a mixed sample of nurses and unqualified staff in UK care homes.

The study also includes the perspectives of relatives of residents about this aspect of care. The principle of relationship-based care is achieving importance in dementia care (Nolan *et al.* 2004). This principle holds that people with dementia, whether living in the community or in residential care, should be viewed in the context of their family relationships. Family members play a significant part in the care of people with dementia, and continue to contribute to their care after their relatives enter residential care settings, as well as having their own needs for information and support. Relatives of residents who display aggressive behaviour will need to cope with that behaviour practically and emotionally, may need assistance from staff in coming to terms with such behaviour and may be able to contribute to the overall care of the person.

There have been few studies to date that have sought the views of relatives of people with dementia about aspects of residential care. Train *et al.* (2005) in the UK interviewed relatives along with staff and residents about their experiences of long-term care, identifying positive and negative aspects of that experience. Some relatives reported continu-

ing psychological distress despite no longer being responsible for the day-to-day care of the person with dementia. Cioffi *et al.* (2007) asked relatives and staff of residents in Australia their views about the environment of a newly built special care unit, finding that relatives were sensitive to the effects of the environment on residents' behaviour.

To date there is no evidence of studies that explore experiences of relatives regarding aggressive behaviour from the patients with dementia in residential care or their views on the management of such behaviour.

Materials and methods

Method

Aims

To explore the views of nurses, and relatives regarding the causes of, and most effective ways of responding to aggressive behaviour from people with dementia in residential care settings.

Design

A qualitative design was employed using:

- Semi-structured interviews with a stratified sample of staff, enquiring about their views regarding the causes of, and best ways to respond to aggressive behaviour by residents.
- Focus groups with the relatives of residents to gain their perspectives on aggressive behaviour and how it is managed by staff.

It was felt that semi-structured individual interviews were the most appropriate data-gathering method with staff, as work constraints were likely to have prevented a number of staff from attending a focus group at the same time. Also, we wished to gain the perspectives of a range of staff grades, as it was felt that junior staff might have been inhibited from expressing their views in the presence of those who were more senior. Focus groups in contrast were selected as the means of gaining the perspectives of relatives as it was considered that they would feel more at ease in a setting that included others in a similar position. In one home, a number of relatives visited on a very regular basis and were keen to be interviewed as one focus group.

Settings

The study was carried out in four nursing homes in the North West of England, UK, that were owned by the same national company. The homes included a total of six dementia care units, ranging in size from 15 to 30 beds. One unit was designated as a Challenging Behaviour Unit.

Table 1

Positions of staff who participated in semi-structured interviews

Position	Abbreviation	Number
Dementia Care Unit Manager	DCUM	4
Registered Nurse	RN	2
Care Assistant	CA	2

Participants

Staff

A convenience sample of staff was sought, embracing qualified and unqualified staff across the participating units. Unit managers were asked to identify volunteers among their staff, with a view to ensuring a mix of qualified and non-qualified staff. Some unit managers were themselves interviewed. A total of eight semi-structured interviews were conducted with staff members, six of whom were female and two male. Ages ranged from 20 to 55. Table 1 gives a breakdown of their positions in their respective homes (and abbreviations of those positions used in the following quotes). This reflected the spread of staff and ratios of the same working in the units at that time. For example, the majority of staff were female and this was reflected in those interviewed.

Relatives

Relatives were written to prior to the commencement of the study as a whole to gain their approval for data collection to take place regarding residents and at that time they were asked to indicate if they would be willing to participate in a focus group. Those who expressed interest were later written to again and formally invited to take part. Two focus groups were held, in different homes. Six relatives attended one focus group (FG1), three male and three female. Relationships included spouse, partner, son-in-law and mother of residents. Two relatives attended the other focus group (FG2), relationships including daughter and niece of residents. Two other relatives originally said they would attend this meeting, but did not do so. As such the carer sample was based upon convenience.

Data collection

Interviews with staff were conducted by a member of the research team, in a quiet room at participants' place of work, using the same standard, semi-structured interview schedule, and were audio-recorded. The schedule was based upon a range of prompts reflecting Duxbury's model (2002) covering the multidimensional nature of aggression causation and management. Interviews lasted between 22 and 52 min. Focus groups were also conducted in a quiet

room at the relevant care home by two researchers, both of whom had conducted the interviews. These were audio-recorded. Both were 45 min in length. Data collection took place between November 2008 and March 2009.

Data analysis

All audio-recordings were transcribed. Content analysis identified key themes in relation to the broad study aims. These themes were refined through discussion among the research team following a thorough review of the literature. The transcripts were searched for 'meaning', 'focus' and 'point' in order to provide a thematic analysis and uncover personal accounts of experience rather than as interpreted by others (van Manen 1997). Thematic statements were isolated and then subsequently became 'objects of reflection'. The participants had the opportunity to discuss the appropriateness of themes by reflecting on groups of statements under a generic question: *is this what the experience is really like?* Thus the interview became an interpretive conversation, which allowed the participants' perspective to be explored and avoided researcher bias. This feedback and discussion with respondents about the trustworthiness of the thematic analysis of their experience supports and validates its credibility as Lincoln & Guba (1985) recommend in their prerequisites for soundness in qualitative research. Certainly at this stage of the research, at the pre-reflective point, it seemed sensible to check with the participants that the findings relate to their perspective and that they summarize the aspects '*worth paying attention to*' (Lincoln & Guba 1985, p. 290).

Ethical considerations

Ethical approval for the study was gained through the National Health Service Research Ethics Committee as well as the University's Ethics Committee, and the research governance forum of the care home company. All participants were given information leaflets about the study and signed consent forms prior to data collection. Participants were assured that they could terminate the interview at any time. They were also told that if anything was said during interviews or focus groups that suggested abusive practice the research team would be obliged to share that information with the care home company.

Anonymity of all participants was assured. Participants will be identified in the following extracts only by abbreviations of their staff grade, or by the identification code for each focus group. Names of individuals have been changed.

Results

There was a notable consensus of views between staff and relatives, and consequently findings from all participants

have been thematized conjointly and are presented together. In the main with regards to views about causation, three triggers were identified:

Causation: the triad: internal, external and interpersonal factors

Triggers that precipitated aggressive behaviour were commonly reported by participants and can be grouped as internal, external and interpersonal triggers.

Internal

Internal triggers, which are those, that are specific to the individual and might include physiological and/or psychological factors are broken down further into two sub-themes. They are frustration and illness both of which were noticeably reported upon.

Frustration

Participants views appeared to reflect the idea that aggressive behaviour could be regarded as a 'poorly communicated need' (Stokes 2000), highlighting the frustration that residents felt when unable to communicate their wishes effectively or their feelings of threat particularly during personal care activities:

I think a lot of it is frustration, whether it's they're frustrated because they don't understand what's going on around them or they're frustrated because they can't explain how they're feeling. (RN3)

She's used to doing things and now she can't and it's all frustration inside of her. (FG1)

Similarly, in addition relatives found that they too had to deal with their own level of frustration concerning the behaviour of their 'relatives or family members':

We've all had that, you know you feel angry towards them, you're tired and frustrated yourself. (FG2)

The relatives shared the view that aggression was an expression of underlying frustration.

He did it because it was frustration really, . . . trying to tell me something, course I didn't know what it was and then used to get really angry because I didn't understand what he was saying. (FG2)

Illness as a mediating factor

In addition to frustration, illness, and in particular dementia, was raised as a factor that can lead to aggressive behaviour. However, while this was a common theme reflecting views that internal factors can be a trigger, participants tended to underplay dementia as a direct cause of aggressive behaviour, regarding it more as a mediating factor, with the specific trigger for aggression being in the situation:

I just think that they get aggressive as a natural . . . anybody would if they are being stopped to do something . . . they might go over the top with their aggression whereas I think if they didn't have dementia, they wouldn't. (CA2)

One of the relatives commented:

Yeah I just felt so guilty about it though, but you know you were reacting as if someone was talking to you in a rational way, now I realise that she wasn't. She genuinely didn't know and it didn't matter. (FG2)

Another found that:

In BBs case there was no aggravation, she was not angry at any time before the stroke, it was only after that time that she became intolerant of things. (FG1)

From a staff perspective one of the unit managers recalled speaking to a resident about his aggression.

I said [to a resident] when you are really, really wound up at the top of your thing, is there anything, is there anything you can think of that would bring you, or help staff to calm you down and he went, 'fraid not it's now the way I am. (DCUM1)

This was echoed by relatives in one of the focus groups: 'Slight personality traits become exaggerated, it all seems to be negative things you know, my mum has never liked change so any change is now a major issue' (FG2).

Environmental

In contrast to internal triggers, environmental factors were also seen to be a cause of aggression. Participants were asked about the environment specifically but mostly raised issues pertaining to physical elements of this. Factors pertaining to the design of the unit particularly with regards to space, both physical and personal were discussed. A number of relatives raised the issue of space:

I mean the thing with an open plan design is that if there's something happening in one corner of the room everybody knows about it . . . somebody starts to shout in one corner it has a knock on effect and everybody starts to shout, including my mum you know. (FG2)

She's never been a particularly social person really, she likes her own space and she's suddenly been thrown into a place where I think she thinks that everybody in there is somehow invading her space and she doesn't like it. (FG2)

One unit had been recently redesigned to incorporate a quiet room. This appeared to have a positive effect. 'Since we have done this we have different options for patients and we can sit quietly and talk to them or they can just come in here and sit, so the level of aggression has come down' (CA 1).

In addition to design and space the culture of the environment can compound aspects of the physical environment as pointed out by another care assistant:

Aggression can be the result of another of things, intervention, invading personal space, being told you have to come to the table to eat, we do give quite a lot of orders, they have got to keep to a routine. (CA2)

Interpersonal

Interpersonal factors were commonly raised by both relatives and staff as precursors to aggression. Clearly this was also tied in with some earlier issues such as frustration; interpersonal communication and personal care needs were seen to be particularly influential.

Interpersonal communication

Both staff and relatives recognized that they themselves could trigger aggressive behaviour through approaching people with dementia in the wrong way:

[You need to know] when to back-off a little bit from somebody who's aggressive, not argue, because I have seen people, they'll labour a point with a resident – 'Now come on Jim, drink your soup up or drink this or drink that.' 'No, I don't want it.' 'Now come on it's good for you. Now come on, we don't want you not eating. You know what your daughter said.' 'I'm not hungry, I don't want it.' 'Well I'll have to tell your daughter,' and it's the attitude of that particular person. (DCUM2)

One relative recalled, 'we used to have horrendous arguments because I would say something . . . like you've already asked me that and she was no I haven't, and she would really lose it. And I've had plates thrown at me' (FG2).

Conversely interpersonal skill can have a positive effect as pointed out by one relative: 'Staff really put 100% in here and they have their own individual patients who they know well' (FG2). It seems to be basic humane things that matter most.

'Usually a cup of tea and a butty solves it,' reiterated one member of staff (SN1).

Personal care needs

With regards to personal care, managing hygiene proved to be particularly problematic for both staff and relatives. One care assistant commented that

He just doesn't like us messing, you know, it is like an invasion of privacy isn't it? I would probably be the same if somebody came and pulled my pants down and started cleaning my backside. (CA1)

A relative relayed her thoughts saying

She also gets quite aggressive when it comes to her kind of personal care really. You know she doesn't like having a shower, having her hair washed. . . . (FG1)

Quite often it's against the staff themselves, particularly with personal care. (FG1)

He doesn't like being handling or anything like that. (FG2)

Frustration again appeared to be part of the problem: It was just frustration, she'd got very violent, in fact she still is especially when they change her. (FG1)

Responding to aggressive behaviour

Responses to aggression could be categorized in one of two ways: a compassionate approach; or 'not going in strong'. Both related to the style of the interpersonal approach adopted by care home staff. The first highlighting the importance of communication and the second reflecting views about the spread of management approaches that can be adopted including medication, and restraint.

Compassionate approach

Staff and relatives agreed that their interpersonal manner was the most important factor in responding to aggressive behaviour. The general view was that staff should stay calm, not argue and 'back off' to prevent aggression getting out of hand:

If [my mother] is really, really getting upset I'll say right I'm going now and I'll go and sit with another resident until she's calmed down and then come back and then it's just as if she's never seen you. (FG2)

Participants in one focus group were unanimous in their admiration for the Unit Manager's approach:

She takes everything in her stride, she does it easily, she's very clever is Anne with all situations. She seems to have compassion . . . everyone seems to love her. You know you can come in here and Anne will be sat there nice and peaceful and yet when Anne ain't on some days you come in and there's one or two playing up. She takes it all matter of fact; nothing seems to faze her. (FG2)

'It's so important not to get angry back' (FG1). 'You can't beat the personal touch' (FG2). Nursing staff responses echoed this. 'Well I think what is important is that we remember they are individuals. They have all got their own personalities, they had all had a life be it good or bad, we shouldn't judge them for their aggression. You know we could be in their shoes one day' (SN 2). This level of empathy was echoed by a senior manager who said 'you have to get to know the patient as an individual, as a person, not as an illness or a risk factor' (DCUM3).

'Don't Go In Strong'

Both staff and relatives felt that controlling strategies (medication and restraint) should be used sparingly as a means of responding to aggressive behaviour. All agreed

that medication should be used to 'calm down' agitated individuals without 'drugging up' and compromising the resident's personhood and it was evident that staff had communicated this philosophy to relatives:

I've been in homes where they've been I would say drugged up. You know they have a policy [here] that that doesn't happen and I admire them for that because they like the person to be the person. (FG2)

I don't think it should just be prescribed as a matter of course really but I think with careful handling there is a role for it. I think if you have asked me that before she went in and before I knew what I know now, I would have said definitely not. (FG1)

The words were actually used . . . we don't want her drugged up, we don't want her dopey . . . which I was impressed with that reality. (FG1)

Participants were similarly wary of restraint as a management strategy, although it was, however, accepted that 'planned restraint', though unpleasant, might be necessary in certain circumstances:

A few months ago she's let her hair . . . she wouldn't have it cut . . . she let it grow for about six months and it was here, and it looked awful, she wouldn't let them wash it or touch her and it eventually got so bad that two of them held her while one cut it. We said if you hold her we're happy, you know, it was awful; it really was awful. (FG2)

Restraint could, however, often be substituted by less drastic controlling strategies:

I don't feel that a lot of physical restraint has been absolutely necessary, you know, I don't feel that is the way. I think 99.9% of the case it'll be talked through or just an arm around a shoulder and brought away, you know. (DCUM4)

Another senior nurse summed it up well saying, 'You don't need to go in all guns blazing. To physically restrain anyone when they're getting violent, it makes them worse. . . . You've got to try and talk to them' (FG2).

Discussion

In an earlier survey of staff attitudes and an audit of aggressive incidents in older people mental health settings the findings indicated that staff were more in tune with a person-centred than a standard paradigm perspective on aggression (Pulsford *et al.* 2011). These findings are reflected in the qualitative data reported upon in this paper.

The interactions between staff or relatives and patients in this instance were regarded as a significant cause of aggressive responses; the environment of care was seen as a trigger of resident-to-resident aggression, in particular and

the person's dementing illness was seen to be a mediating factor. Aggressive behaviour is largely seen by staff and relatives as being need-related; the person's need generally being to relieve frustration or remove perceived threats. It is principally an interpersonal phenomenon, and therefore best responded to by interpersonal means. Where provoking factors were evident, these tended to be attributed to occasions of personal care, interactions with other residents or the person being denied something by staff. These factors have been identified as significant triggers for aggression in other studies (Almvik *et al.* 2006, Whall *et al.* 2008). At the same time, in the staff interviews, some aggressive behaviour was felt to be difficult to explain and some residents were regarded as being prone to aggressive outbursts as a result of biographical factors (for example, a resident who was a former professional boxer).

Participants in the interviews and focus groups regarded interpersonal means of responding to aggressive behaviour as being the strategy of choice in the first instance, reflecting a desire to maintain the dignity and personhood of the individual. The approach was all important, and involved keeping calm, 'backing off' rather than arguing back with residents and using de-escalation and distraction techniques. Participants pinpointed other factors that were important to successful aggression management, including learning from experience, good teamwork and consistency of staffing, allowing staff to get to know residents well. These principles all reflect best practice in dementia care (Kitwood 1997, Stokes & Goudie 2002). Whittington & Wykes (1994) have also commented on previous research in aggression in acute care mental health settings reporting that staff have a tendency to 'go in strong' in order to cope.

In this study staff were less inclined to share supportive views about controlling strategies such as use of medication and restraint. It is likely that some residents received regular doses of tranquilizing medication, but there were indications that this was generally kept to a minimum. There was a clear ethic, communicated to and accepted by relatives, that residents should not be 'drugged up', but should be allowed to retain their personhood and express their character. It would appear that concerns recently expressed in the UK regarding the overuse of medication in care homes (All Party Parliamentary Group on Dementia 2008) may not apply to the homes in this study.

It was accepted, however, that controlling strategies might need to be used in some circumstances. Restraint was used more than medication as a controlling strategy, the reason perhaps being, as one Unit Manager opined, that a few minutes restraint was preferable to the person being sedated for hours. Staff disliked restraint, but accepted that 'planned restraint' was sometimes necessary for reasons of

safety and maintaining dignity during personal care activities. In some cases, however, creative ways of distracting residents were found that reduced the need for restraint. It was evident that relatives had some involvement in decisions regarding restraining residents.

The findings from the staff interviews may be compared with other qualitative studies. Comparable views were expressed by care assistants in a study by Manderson & Schofield (2005). A key emphasis was that residents should not be blamed for their aggressive behaviour, which was regarded as being largely due to situational factors, and that walking away from an aggressive resident was the best initial response. By contrast, the care assistants in MacDonald's (2007) study displayed a sense of nihilism; despite awareness training in person-centred care they retained a negative, 'standard paradigm' view of residents, and a lack of awareness of their own contributions to triggering aggression. The factors in the climate of care that may underpin these differences in perspective warrant further investigation.

Our study is one of few that we know of to seek the perspectives of relatives of residents regarding aggressive behaviour. The participants in our focus groups displayed a gratifying level of awareness of the interpersonal aspects of dementia care and there was clear evidence of their understanding of, and participation in care decisions. Overall, the principles of relationship-based care were apparent in the participating care homes.

The study has a number of limitations. It was conducted in a small number of care homes; all owned by the same company, and may not be representative of all UK care settings. A small number of staff and relatives took part. Also, participants in interviews and focus groups were volunteers and might not represent the views of all staff or relatives. Furthermore, it has not been underpinned by a systematic review and papers which were not written in English were excluded thus there may be some key international research that is missing.

Conclusion

The qualitative data from staff interviews reinforces our previously published survey findings that aggression management, while pragmatic and eclectic, broadly follows person-centred care principles (Pulsford *et al.* 2011). This was reiterated by relatives who were supportive of the focus on using interpersonal skills to manage of aggression, and in person centred care. Our study adds to the sparse literature regarding aggression management in care homes and the lack of commentary sought from participants. While the results of both this and our earlier study are promising suggesting a less coercive approach to this aspect

of dementia care, given the limitations of this relatively small and regionally located sample, more research of a similar type is required in order to provide greater exploration of key issues across a range of care environments such as the importance of person-centred philosophies of care and addressing environmental challenges. Additionally and more importantly, endeavours should be made to ascertain the views of residents with dementia themselves. The literature in this area is limited but given changes to mental health law and the introduction of the importance of consultees, this is possible particularly if using more

creative research methods such as photographs, media and/or art. Additionally with the introduction of memory assessment centres there is more scope to access people at the early stage of dementia where views could be canvassed while an individual has reasonable cognitive ability.

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