

A different story: exploring patterns of communication in residential dementia care

RICHARD WARD*, ANTONY A. VASS†, NEERU AGGARWAL**,
CYDONIE GARFIELD*† and BEAU CYBYK*†

ABSTRACT

This article reports findings from a three-year project on ‘Communication patterns and their consequences for effective care’ that explored communication in dementia-care settings. As the proportion of people with dementia living in British care-homes continues to grow, there is a need to understand better their care. Using a range of qualitative methods, the project set out to identify the constituent elements of dementia-care practice and the patterns that characterise day-to-day relations in care homes. The tightly prescribed and standardised nature of the interactions between staff and residents is described: it raises questions about the capacity for dementia care to be truly person-centred. The project found that people with dementia are both capable of communication, and invest much effort in seeking to engage those around them, but are excluded from the monitoring, planning and provision of care in ways that we argue are discriminatory. The case is made for promoting and supporting communication as key skills and competencies for care workers. The value of measuring the level and quality of communication as a means to evaluate care is demonstrated. The authors question the priorities that currently guide care practice and argue that we need to listen to people with dementia and rethink what lies at the heart of dementia care.

KEY WORDS – dementia, Alzheimer’s disease, care homes, communication, care work, disablism, person-centred care.

Dementia, communication and residential care

It is estimated that three-quarters of the residents of United Kingdom care homes have dementia, and it has consequently been argued that ‘dementia care has become the main business of almost any residential or

* Centre for the Older Person’s Agenda, Queen Margaret University, Edinburgh, UK.

† School of Health and Social Sciences, Middlesex University, Enfield, London.

** The Alzheimer’s Society, Islington, London.

*† Jewish Care, Golders Green, London.

nursing home for older people' (MacDonald and Dening 2002: 548). This paper examines the constituent elements of dementia-care practice by focusing on the core patterns of day-to-day relations in care homes. The aims are to reveal the priorities that govern the provision of care to people with dementia, and to consider what aspects of that care warrant greater support and recognition.

For at least 20 years, a growing body of research has sought to measure and quantify the experience of institutionalised forms of care for older people with dementia (*e.g.* Godlove, Richard and Rodwell 1982; Hallberg, Norberg and Eriksson 1990; Bowie and Mountain 1993; Gilloran *et al.* 1993; Nolan, Grant and Nolan 1995; Schreiner, Shiotani and Yamamoto 2005). These studies, which have employed mainly observational techniques, have focused upon various aspects of daily living including levels of engagement, activity and communication, and correspondingly have offered indications of the extent of inactivity and isolation as an everyday feature of the lives of residents. These research findings amount to a consensus, which is typified by the concluding remarks of a recent Japanese study: 'most Alzheimer's residents continue to spend their days alone, doing nothing, with little social interaction; and what we call "null affect" is probably concealing much more sadness and loneliness than we would care to admit' (Schreiner *et al.* 2005: 134).

As this body of evidence has been gathered, there have been many changes in welfare policy and in the monitoring and scrutiny of care homes. Similar findings have been reported on several continents, suggesting that differences in welfare systems have little impact upon the day-to-day experiences of those residing in care. Such consensus implies that there are certain attributes to institutionalised care that are seemingly immutable and fixed across time and place. Several studies have addressed the dynamics of care and shown a disparity between the socially-oriented interests of residents and the task-based agenda of the care staff (Bender and Cheston 1997; Edberg, Sandberg and Hallberg 1995; Grainger; Atkinson and Coupland 1990; Iwasiw and Olson 1995; Small *et al.* 1998).¹ The content of caring encounters and their relation to the wider conditions of care homes or hospitals have also been explored (Coupland *et al.* 1988, Lanceley 1985), but no discernible flow of information is evident from research into practice about what lies behind the deficiencies of staff-resident interactions. Why they persist in their current form or how they might be altered remain unanswered questions: it is simply accepted that current practice is poor, and assumed that this reflects poor training, inadequate pay and working conditions, as well as popular prejudices about caring for older people (MacDonald 2005).

The ‘Communication patterns and their consequences for effective care’ project

This paper reports a collaborative study between researchers at Middlesex University and Jewish Care, the host organisation and largest provider of health and social care services for the Jewish community in the United Kingdom. Jewish Care offer a wide range of services including the provision of long-term care homes for older people. The ‘Communication patterns and their consequences for effective care’ (CPCEC) project, a three-year investigation during 2000–03, examined communication by and with people with dementia in various types of care setting. This paper focuses on the data generated from the first and main phase of the project, on residential dementia care. Phase 1 of the project gathered evidence of the differing standpoints of those who work and live in residential care settings and examined organisational practices. A full report was delivered to Jewish Care, which led to the formation of a ‘Dementia Development Team’ that now utilises the findings to enhance dementia-care practice throughout the organisation. It is beyond the scope of a single paper to give a full account of all the collected evidence, so this paper focuses on three themes.

First, drawing principally from the video data, we outline the everyday practices and patterns of interaction in residential dementia care. Although routine care encounters have been observed and noted by a host of international studies of dementia care (as reviewed by Brooker 1995), to date they have received little critical attention. Secondly, we compare the content of the interactions between care workers and residents with the care-workers’ accounts of their workplace experiences. Finally, we present evidence in support of the growing call for more attention to the ability of people with dementia to maintain communication (irrespective of the severity or nature of the impairment).

Design and methods

The agreed aim for the CPCEC project was to develop a more detailed understanding of what happens in dementia-care settings; what goes on when a care worker and a resident with dementia interact, and what can be observed and understood of the experiences that people with dementia have of their care and the settings in which it is provided. In doing this, the aim was to build a picture of dementia care that would assist critical thinking about care practice and, in particular, to identify those aspects of care which could be improved. The project was designed to focus upon patterns of interaction in care and associated daily practices. The

rationale was that the features of caring relations that were repeatedly witnessed were likely to be defining qualities or characteristics of dementia care.

The study sought to make a contribution to the small but growing body of evidence on communication in dementia-care settings (*e.g.* Goldsmith 1996; Hamilton 1994; Killick and Allan 2001). Drawing from authors that have argued it is both valid and helpful to consider various types of expression and behaviour by people with dementia as forms of communication (Hallberg, Norberg and Eriksson 1990; Hallberg *et al.* 1993; Kitwood 1997), we sought to test the specific hypothesis that, 'irrespective of the severity or nature of impairment, a person with dementia will seek out and establish a means of self-expression and thereby make every effort to maintain a relationship with the world they inhabit'.²

The research process and sampling

The project began with the development and ratification of a detailed ethics protocol, a full account of which is published elsewhere (Vass *et al.* 2003). The project was divided into three phases, each of which examined patterns of communication in different settings; first in residential care, then in different types of day care, and finally in home care. At the time of the research, Jewish Care owned and ran 11 care homes registered to provide residential, dementia and/or nursing care. The homes varied in size from 40 to 120 residents, and approximately 75 per cent of the residents were funded through the statutory health-care and social services agencies.

The sampling frame was a list of the 594 staff employed in both care and non-care capacities across the 11 homes (with ethnicity and gender recorded). From this list, 123 staff were randomly selected, including 28 men (23 %) and 95 women (77 %). The sample included care assistants, night care-workers, group leaders, qualified nurses, home managers, assistant managers, and various non-care workers such as domestic staff, administrators, maintenance workers, laundry assistants and dining-room co-ordinators. They were invited to a general meeting to discuss the project, and offered the opportunity of a one-to-one meeting with a researcher at which they could raise questions or concerns. The research team also gave presentations about the research at each of the homes included in the study. Following the consent gathering process, 32 care staff and six non-care staff agreed to participate in the project. All were interviewed using a semi-structured interview schedule, with an abridged version for non-care staff.

Turning to the residents, a sample frame was identified of 17 men and 78 women with a formal diagnosis of Alzheimer's type dementia among the residents of Jewish Care's facilities. From this pool, 28 (five men and 23 women) were randomly selected for the study. Once selected, the research team initially approached the next-of-kin (or guardian) of each resident to seek consent for the resident's participation. In so doing, the next-of-kin were asked to participate by giving an interview. Once consent was received from the next-of-kin, a member of the research team approached the resident, providing information on the project and asking for their consent to participate. It had previously been agreed that if either the next-of-kin or resident declined to give consent, the resident in question would not be included in the project. After consents had been obtained, 17 residents (two men and 15 women) were recruited. The five study homes (and eight care units) were those in which the sampled residents lived. Two were dual-registered, two registered as care homes and one as a care home with nursing. The five ranged from 40-bed settings to self-contained units with only nine residents. Some of the care homes we visited were purpose-built while others had been converted from other uses.

Data collection

The residents were filmed in communal day rooms where also researchers observed and recorded interactions and daily events. Each resident was filmed over four-and-a-half days between 07.00 and 19.00 hours, with at least one researcher always present. The cameras were fixed to the walls of the day rooms of each unit. Throughout the design period and during the fieldwork, the team had to balance ethical considerations with the ambition to generate an accurate picture of residential dementia care. In addition to the continuous monitoring of the wellbeing of the participants, it was agreed that no filming would be undertaken in private spaces, such as residents' rooms, or of the more intimate forms of care, such as dressing, bathing and assistance with using the toilet. The data presented here are therefore based exclusively upon observations and filming in communal areas of the homes, and the measures and timings that follow omit those periods when residents received care elsewhere in the homes.

To provide an overall picture of life in the residential care facilities for both staff and residents, the video data were supplemented with diary observations of the routines and day-to-day activities on each of the residential units. Eleven volumes of diary observations were compiled and they have nearly 1,400 entries. Access was also provided to the documentation held by the care homes on each of the sampled residents. Where possible, efforts were made to interview or to conduct shorter

exchanges with the participating residents. In summary, the data gathered for the first phase of the CPCEC project included:

1. 32 semi-structured, in-depth interviews with randomly-selected care staff, and six interviews with non-care staff.
2. 18 semi-structured interviews with next-of-kin.
3. Interviews and/or a series of shorter exchanges with 17 people with dementia.
4. Over 300 videotapes (equivalent to over 1,000 hours of recording).
5. 11 volumes (more than 2,000 pages) of observation diaries.
6. Records of the structure and content of 17 files and care plans.

Analysis

The interview data were coded using NUDIST software and the themes that emerged were cross-referenced with other sources of data including the textual analysis of care-home documents. A comparative analysis of the interviews conducted with staff, next-of-kin and residents was undertaken. Findings from the observation and video data were used to confirm the interview evidence and to pinpoint areas of dissonance. Approximately 230 tapes (excluding those from pilot studies) were amassed during the fieldwork, from which archive at least three were systematically selected for each residential unit. This ensured that different times of day and each participating resident were represented on at least one tape. In all, 30 tapes with over 100-hours of footage were scanned using event sampling to note and time each discrete interactional episode.

To analyse the video data, the team (including representatives of Jewish Care) used a modified version of the 'Quality of Interactions Schedule' [QUIS] (Dean, Proudfoot and Lindesay 1993). Diary entries were also coded according to QUIS headings, but one problem was encountered: one of the most prevalent 'activity states' that was observed was social isolation, but it was not a given category. An additional category, 'neutral-neutral', was introduced for periods where no observable communication took place.³ High levels of concordance between coders were achieved but some difficulties remained with the coding tool. The differentiation of 'neutral-neutral' periods from discrete episodes of interaction was problematic. Another major concern was that there was a great deal of interaction (especially at the non-verbal level) that we found difficult to record and interpret. Throughout the 'neutral-neutral' periods, people were moving, gesturing, nodding their heads, observing and acknowledging one another, listening and reading. In sum, we realised our own shortcomings in recording communication and social interaction and the limitations of

pre-defined categories. It was clear that an exclusive focus on the (more easily interpreted) contact between staff and residents would fail to capture the essence of what had been observed and recorded.

Two stop-watches were used to time precisely the durations of the residents' direct communications and of the spoken inputs (or talk) that formed elements of these encounters. A tally was also kept of the frequency of the interaction episodes. A second analysis of the video data was undertaken by one member of the research team. This scanned the entire stock of video tapes using event sampling and each episode of interaction was classified into one of three categories:

Task-based, i.e. encounters characterised by a focus throughout on the task at hand.

Social or relationship oriented, i.e. encounters not observably motivated by the need to undertake a care task and where the content was not task-related.

Combined, where task-based episodes of interaction were observed to include social and/or relationship oriented communication.

Once classified, episodes illustrative of each heading were transcribed and examined in detail for both verbal and non-verbal content. The observational diaries and interviews were also used to support more detailed scrutiny of the filmed self-expressions and interactions of the residents. Given the individual and diverse forms of the recorded expressions, analysis and interpretation of video data was at various levels for different residents, but the findings were systematically organised to identify the patterns in the self-expressions, the interactions and in the responses to the (social) environment.

The findings

This section reports the findings from the video data and observational diaries, which are illustrated with extracts from the interviews. Most residents spent the best part of the day in the communal areas of each unit, where the filming took place. As the carer interviews revealed, however, certain episodes of personal care (not recorded) could present crucial opportunities for sustained interaction between staff and residents. Many carers specifically cited bathing as being amongst the most important occasions for individual forms of communication:

When I give them a bath, it's the most intimate time, the one thing that you do together and they've got you all on their own and they love having that one-to-one contact. They come out with more things when they're having a bath than they do when you're just sitting there (Care worker).

We identified the *core patterns of interaction* in residential care. The analysis of the video data revealed that people with dementia on average spent

10 per cent of the day in direct communication with others. The timings revealed much individual variation in the overall levels of interaction and the relative frequency of different types. Regular visits from friends and relatives, as well as close friendships with other residents, raised an individual's level of interaction. However, those who required assistance to mobilise were observed to move around the care home less and to exercise less choice over where and with whom they sat.

One project participant was a member of a small network of friends who were observed in the group management of impairment. Mobile members of the group assisted those who were in wheelchairs; those with better memories reminded and reassured others who had forgotten family visits or the time of day; and two group members clarified and repeated the comments of a third who had suffered a stroke, to facilitate her participation in conversations. Strategic positioning also played a part in influencing levels of daily interaction. One project participant sat next to a doorway that linked two communal rooms, which enabled her to engage care workers repeatedly in brief exchanges as they passed by. We also observed that some residents congregated around the foyer and main entrance door of their home, which meant they encountered people arriving and leaving and enjoyed higher levels of communication than those who sat in the day rooms.

Direct contact with care workers occupied on average 2.5 per cent of the day with little variation. The analysis of the video data revealed a low frequency of interactions between care staff and residents. Over the 12-hour observation period, the average number of discrete episodes of interaction was 17.7 per resident, of which 12.9 were initiated by care staff and 3.1 lasted no more than five seconds. On average, 2.3 of these encounters were wholly silent, with no verbal input from either worker or resident. Thus, most contacts were initiated by care staff but they tended to be brief and some were entirely silent. Of all carer-initiated interactions, 77 per cent were coded as task-based, 15 per cent were social or relationship oriented, and eight per cent combined a task-based encounter with social or relationship-oriented content. By timing precisely the duration of the spoken content in these encounters, it was found that only approximately one-third of the contact time between care staff and residents involved verbal exchanges. Thus, silence is the dominant mode of caring encounters.

The residents appeared to exercise little choice in the timing and provision of care and the observed care episodes unfolded at a pace set by the staff. Overall, the video evidence pointed to a standard form of engagement between staff and residents, despite marked variations in the residents' communicative and cognitive capacities. A core pattern of encounters, organised according to a daily sequence of tasks, lies at the

heart of dementia care. Elsewhere we have described this pattern as ‘the mantra of dementia care: out-of-bed – wash – dress – feed – toilet – back-to-bed’ (Ward *et al.* 2005). The video films revealed a common format and a predictable sequence to most of the encounters. Both residents and carers had a tightly-defined role to play in these encounters from which they rarely departed. The analysis has concentrated on the most representative and common attributes of communication between staff and residents, but the videos also captured less frequent encounters, during which moments of tenderness and warmth were communicated verbally and non-verbally, and which often led to clear signs of wellbeing for the resident. There were also occasions when workers successfully engaged residents in sustained interactions and managed to overcome a host of communication challenges. In our opinion, there is much potential benefit to be derived from close scrutiny of these exceptional encounters.

‘Care-speak’ or how to get things done in dementia care

The residents of the studied care homes had variable levels of impairment and related needs. According to our interviews and conversations with them, many craved the opportunity to be socially engaged. Despite this, a focus upon the efficient completion of a daily sequence of care tasks was managed and maintained by the staff and wider organisation. Accordingly a great deal of time, effort and skill was invested in maintaining a certain order of relations in care. How did staff maintain order and fix relations in these brief encounters? Despite the varied nature of the tasks that the workers were required to undertake, it was evident that interactions with residents had four main components:

- An opening.
- A signal of intent.
- Accomplishment of the task, and
- A closing remark or gesture.

Our observations found that it was not uncommon for some or all of the sequence to be performed non-verbally using gesture, guiding touching and physical handling. When a resident complied with a task and showed knowledge of the routine, often the carer’s speech was minimal. The single most frequent predictor of greater levels of spoken input was when a resident *failed to comply with a task*. When undertaking tasks, the care workers were observed to employ a distinct style and pattern of speech, which we labelled ‘care-speak’. Over-riding differences in gender, ethnicity and age, care-speak was used by workers in all the studied homes. It is characterised by a series of directives, framed by narration of the task at hand and

punctuated by words of encouragement. During these episodes, verbal input by the residents was rarely required and not often elicited. An example of the directive speech of one care worker follows:

Mary, that's right Mary, we're going to sit over there ... this foot forward first, slowly and then this foot. Well done, now I want you to turn, you're going to turn towards me and then put this foot here, no here, that's right and a little shuffle and just lower down, back from me now, in there, lovely.

When speech featured in task-based encounters, this form predominated. Such guiding narration of the task at hand might be considered good practice, not least when working with individuals with cognitive impairment. When, however, other forms of engagement were absent, there are clear implications for the social experience of the people with dementia. The speech form constrains input by the residents when tasks are undertaken, the result being that during the very limited periods of engagement between staff and residents, there was little opportunity for a resident to make an active contribution. Care-speak also ensured that there was little space during the contact for talk about non-task topics. This standard form of communication limited the opportunity for personal inputs by care workers. In effect, from the standpoint of the person with dementia, one encounter with a care worker was much the same as the next. Despite the variable size and level-of-care provided by the eight care units in the study, we found that the daily levels of direct contact between staff and residents differed minimally from one setting to the next.⁴

In order to ensure compliance during the provision of care, staff drew upon what seemed a well-rehearsed tactical repertoire. The video analysis revealed four types of response, although from an observational standpoint one cannot be certain what factors influenced the choice of response:

- 'Desistance' (*i.e.* desisting from or postponing a task). This was the least frequently observed but arguably the option that most readily recognises the will and agency of a resident.
- Verbal persuasion. This was common in all the homes.
- Coalition, when a second and sometimes even a third carer would contribute to the persuasion.
- Enforcement using authoritative commands or by physical presence, for example when keeping residents in position during the provision of care.

The narratives of care workers: what is dementia care?

Current research in the field of dementia is characterised by an absence of attention to the perspectives and experiences of paid care-workers. Little is

therefore known about how carers make sense of what happens in care settings. There is evidence that care workers are offered few opportunities to reflect upon their work or to share insights into the challenges they face (Berg, Hallberg and Norberg 1998). The interviews with the care workers were designed to elicit a comprehensive account of their experience of the dementia-care dynamic. Several broad topics were addressed, including issues of communication, interactions with and between residents, staff relations, relations with the wider organisation and their knowledge and understanding of dementia. The carer interviews revealed some dimensions of care work that we were unable to observe or film.

The challenge of dementia care

The carers spoke of the emotional dimension to their work and the personal costs it entailed. Many highlighted the tension between the task-based, instrumental forms of care they felt under pressure to provide and their wish to spend time building relationships with the residents. There were clear indications that carers felt their style and patterns of working were not fully under their own control but shaped by the wider organisation and care system. They said that workload pressures precluded sustained interactions with individual residents. The challenges associated with communication, the difficulties arising from miscommunication, as well as the many levels at which communication can and does take place, were outlined by carers in a manner that highlighted the specialised nature of their work and skills. If it is accepted that dementia care is the 'main business' of care homes, then there is a strong case for promoting and supporting these skills and prioritising their development through training and supervision.

The interviewees reported having to manage their emotions by undertaking a form of emotional labour; they also spoke of investing their emotions in the residents for whom they cared, which of course entailed negative consequences when a resident died or her or his health deteriorated.⁵ The care workers also described communication at the level of the emotions in dementia-care settings. When usual channels of communication were no longer an option, care workers signalled the importance of responding emotionally to the residents. As one care worker put it:

She was sitting there crying and it was really hard to sort of see someone in such distress and not be able to help them. I mean, I was just sort of hugging her, but I couldn't find out what caused it and never did.

Several interviewees had the perception that people with dementia are attuned to the emotions of others and respond to the moods and feelings

displayed by those around them. One care worker explained very well how this realisation affected their care practice:

When we come out of the office happy, I don't know how to say it but the resident can sense, [can] pick up on you. ... Especially on this unit, [we] need to be the happy staff [because] people will really sense it.

Implicit in these responses is a sense that in dementia care there is a need to present a stable and positive affect, echoing the ever-smiling persona adopted by the flight attendants that was described by Hochschild's (1983) study of emotional labour. The care workers' accounts appeared, however, to depart from the usual understanding of emotion as a (private) psychological state. Instead, in many of the interviews we undertook, emphasis was placed upon the sociality of emotions. In other words, emotions were presented as shared and having currency in dementia-care settings, as forming the substance of relationships and being a vital means of maintaining a social presence by or for the person with dementia.

The order of care

Care work was structured to maintain order at several levels. Some carers told us that they intervened when residents argued and, in this way, maintained emotional and interactional order in the communal area. One care worker lucidly explained the rationale:

Well sometimes, if there's two residents sort of like arguing with each other, you have to come between them, try and calm one down and try and calm the other one down ... but that's if there's someone there, what they would be like if there was no one in the lounge? They could be doing all sorts of things (Care worker).

Notions of the good and bad resident were also signalled during the interviews and were differentiated by the comparative levels of attention they requested. Labelling residents as 'demanding' or 'attention-seeking' revealed the carer's perspective on the legitimacy of a resident's needs and demands. We observed that these notions carried through into everyday practice, there being instances of care workers refusing requests for assistance or attention on the grounds that they were out-of-turn or excessive.

Bodily order and the erasure of need

The outward presentation of the residents' bodies was also a key site for the maintenance of order. Echoing Lee-Treweek's (1997) notion of the 'lounge-standard resident' (see also Reed-Danahay 2001), the interviews with the care workers underlined the extent to which appearance and presentation served as a barometer of the provision and quality of care.

One carer described her response to the changed appearance of a resident she had cared for who had subsequently moved to another unit:

When I go down there, her hair is looking so stringy and everything. Every morning, every day, most of the morning I come in, I try to shower my residents and wash their hair, blow-dry it, set it and everything. I go down there and look at her: *she's a completely different person* (Authors' emphasis).

This theme of the well-turned-out resident as an indicator of not only the good quality of the care but also of wellbeing was echoed during the interviews with the residents' relatives. One signalled the importance of smartness and presentation in judgements of care. Speaking of her father, one woman said 'he was more unkempt at [a previous home] than he is here. He's nicely dressed here and he looks comfortable, so I wouldn't want to change it. I don't think there's any need to change [move him to another home]'. Another relative revealed the significance she attached to presentation even though the resident had indicated a desire to be elsewhere:

She always seems quite well turned out and, you know, clean. We go up there, upstairs, sometimes [and if there are] some clothes hanging on the wardrobe door, you know that somebody's going to come and dress her shortly. I think she's quite relaxed and contented. She'd rather be somewhere else, but doesn't realise the realities of being somewhere else.

It is important not to downplay the emphasis placed by relatives upon how maintaining a clean and smart appearance supported an expected form of (embodied) biographical continuity. Our view, however, is that the absence of effective communication led to the residents' bodies acquiring a symbolic value in care homes. These clean, well-groomed and smartly-dressed 'bodies' not only act as indicators of a certain quality of care, they are the objective of the care. Many of the other individual needs of residents seem to have been erased and substituted by the value attached to physical and social order. We found this unquestioned drive to maintain order at every level of dementia care.

Environmental order and panoptic control

The descriptions by the care workers of the maintenance of order corresponded with our observations of the management of care settings, their layout and movements within them. In all eight of the studied units, the seats were arranged side-by-side in rows and were mainly against the walls facing the centre of the room. This arrangement clearly inhibited interactions among the residents. Where the seats faced one another, the wide space between them allowed the free passage of wheelchairs but impeded interaction. This layout also enabled the carers to survey the residents and take stock of their welfare without direct engagement.

Regulated in their use and occupation of space and their movement around the home, the residents were restricted by both physical barriers and the care workers' interventions. Those residents found walking the corridors were routinely led to the seating areas. One of the most frequently heard carer's instruction was that a resident should 'sit down', even though most residents spent a large portion of the day seated. Care workers were observed deflecting offers of help from residents, who were barred from entering kitchens, laundry rooms and offices. On some units during the day, the doors to bedrooms and those leading in and out of day rooms were locked or in some way secured.

The data suggest that the maintenance of order is a driving force behind dementia-care practice. The day-to-day provision of care is organised according to an array of signifiers that function to reassure care workers, relatives and the wider organisation of the quality of care. The staff and relatives were far less questioning of the levels of contact and engagement. We found little evidence to suggest that these priorities were consistent with the expressed wishes and preferences of residents themselves. Indeed, when considered from the standpoint of communication, the orderliness of care homes presented a host of artificial barriers that adversely affect communication and meaningful social interaction.

Patterns of self-expression

There is growing recognition of the importance of attending to non-verbal forms of self-expression and communication used by people with dementia. In a study undertaken in Canadian care homes, Kontos (2004: 835) argued: 'Slight head nods, eye and small lip movements, chin thrusts, shoulder nods, hand and finger movements, as well as leg and foot shifts were intentional, informative, communicative and interactive'. The few available accounts of studies that set out to explore and describe non-verbal communication by people with dementia have largely sought to compile a typology of its different forms (*e.g.* Hubbard *et al.* 2002). The use of video-film enabled the CPCEC project to scrutinise the self-expression of individual residents over time, to identify patterns of this behaviour, and to consider what changes in the manner of self-expression signify. Indeed, we argue that it is often the changes and adjustments to self-expression made by people with dementia that carry the most important information and insights into their experience and welfare. For instance, one resident repeated the same two words throughout the day but variations in the tone of her voice signalled changes in her mood, wellbeing and need for assistance.

The majority of the residents with dementia did not communicate verbally in a manner that was readily understood by those around them. Self-expression took many other forms, although for many individuals one form of expression was dominant and this differed from one individual to the next. Overall, we were struck by the diversity of expressions and the importance of paying close attention at an individual level. Similar types of self-expression appeared to mean something different from one individual to the next. For every resident in the study, we observed what we took to be intentional, sustained and interactive self-expression. We have attempted to reach tailored and individualised interpretations of each resident's self-expression and now present a case study of one participant.

Michael's self-expression

Michael had been a resident for over three years.⁶ We were informed by care workers that he was 'unable to communicate'. This assumption was reflected in the staff's comments and recorded in his file and care-plan at each stage on the 'pathway' of assessment, placement in the home and care-planning. Michael appeared unable to communicate through speech, his facial expression altered very little, he was unable to turn his head, and his body was stiff. He required a wheelchair to move about the home. There was observable movement in his arms and legs but he did not seem able either to call out or to wave his arms. In common with many of the residents with severe dementia that we observed, there appeared to be no agreed signal by which Michael could attract the attention of staff, so contact was mainly initiated by the care workers and he had little apparent control of when this occurred.

Michael would sometimes slide down in his chair. Each time this happened, carers helped him sit up straight again, and habitually paused to say a few words or hold his hand. This sequence occurred repeatedly and was the only way Michael seemed able to influence the contact he had with staff. We began to suspect that initiating this chain of events was an intentional act of communication on his part. As Michael sat watching the day's events, he would unfold his arms and his legs would jerk and twitch. When certain pieces of music were played, he tapped his hand or foot in perfect rhythm to the music, demonstrating control over this movement. Each time he first caught sight of his wife when she visited, his movements quickened. When she left, his movements slowed and sometimes completely ceased. During the week's filming, Michael's movements had a distinct pattern. They were associated with these key events and we identified rudimentary connections between his movements and the events. We used these patterns as a way of beginning to interpret certain

messages. For instance, more intense movements seemed to indicate excitement, while the slowing of movement seemed to signal sadness or low-mood, especially following the departure of his wife.

As with many of the people who took part in the project, very few efforts were made by the care staff to interpret these patterns of self-expression. Michael's movements were viewed as involuntary and attributed to his dementia; the possibility they might hold meaning and be a key to understanding his thoughts and feelings was generally discounted. There was no evidence in his file to suggest that any structured form of observation, interpretation or recording of these patterns had been attempted. As a result, Michael's efforts to engage with others were frequently overlooked. For Michael and others in similar situations, periods of low mood or worse failed to attract the reassurance of a comforting response from those around him.

The staff's closer engagements with residents

Our observations and the video film did reveal instances of carers who had established a close relationship with a resident (often as their key-worker) and who responded to the patterns of expression that we interpreted as the means of maintaining communication with the individual concerned. These relationships were isolated, however, and it appeared that the knowledge associated with them was seldom shared. This impression was supported by our interviews with care workers, many of whom seemed to struggle to put this aspect of dementia-care practice into words. One care worker's account shifted from an individual to the generality of the residents:

One of them, I could tell what she wanted by her eyes, the way her eyes were, but I don't always know how I did it, but you can tell by the expression in their voice.

Such comments suggest the need for a more widely accepted vocabulary by which to describe the detail of communicative encounters in dementia care and for a support system that records and shares these skills. In short, care workers need time to reflect upon and discuss communication with the residents. The research found that there was very little formal support for developing communication skills. In fact, many of the practice documents used by care homes routinely label people with dementia as unable to communicate or express themselves. This presumption was by no means confined to care workers, as a phrase from a social worker's assessment showed: '[The client is a] charming man; he discourses in a long and involved way and is talking total rubbish'. It was clear that from their arrival in the homes, many of the residents were deemed incapable of making a contribution to crucial decisions affecting their lives. Another

written comment, from a resident's placement review, characterises the attitude: 'Mrs X is sadly unable to express her views due to her mental state'. Nor were they considered capable of participating in the inspection process. As one of the inspection reports noted:

The inspector attempted to interview six service users. However, with one exception, all of them were unable to express an opinion because of their dementia. Three relatives were interviewed. The comments received were positive and indicated that they were satisfied with the care provided. (Commission for Social Care Inspection, Report of Announced Inspection, participating care home).

The slight attention given to the residents' self-expression effectively excludes people with dementia from any form of participation in or influence over the support they receive. This amounts to social exclusion in an absolute form. Such routine exclusion represents what might be described as 'cognitive disablism', and is an example of the discrimination faced by people with dementia in their everyday lives. There is a pressing need to move beyond the expediency of labelling the person with dementia as unable to communicate and to seek out the means by which to recognise, support and facilitate their input.

Discussion

Care-speak is a particular form of 'institutional talk' that is used by care staff to manage the tasks and requirements of their work (Drew and Heritage 1992). Heritage (1997) suggested that repeated participation in a particular type of encounter has a 'wind-tunnel effect'; that is, it generates knowledge of the likely responses and an understanding of how certain ways of managing an encounter minimise resistance or argument. Encounters between staff and residents in care homes become standardised through such repetition, and in the process are normalised. These routines are shaped by and reinforce the context, and the emphasis that they receive is rarely questioned or problematised. As Butler (1993: 9) proposed, the performative repetition of norms serves 'as a process of materialisation that stabilises over time to produce the effect of boundary, fixity and surface'. In the settings we observed, the biomedical model of dementia is the normative framework for the care and is constantly reiterated. In our view, the patterns of engagement that we identified and the work invested in maintaining their standardised form is what connects institutionalised dementia care across time and place and may explain why strikingly similar conditions have been reported in many developed countries.

Much of the strength of the CPCEC project lay in its combination of various qualitative approaches that gathered data from multiple perspectives. This eclectic evidence revealed that more than one version of the reality of staff-resident interactions in residential care settings could be constructed. Indeed, different standpoints led to highly contrasting accounts. Our own observations and filming most closely supported the comments and impressions offered by the people with dementia who participated in the project.⁷ Their total exclusion from the planning and provision of care is all the more questionable as a result. As the social model of disability gradually becomes more influential in thinking about, and the practice of dementia care, a very different framework for interpreting conditions in care homes is emerging. This includes acknowledging that ‘people with dementia are discriminated against and marginalized’ (Mary Marshall 1994, quoted in Gilliard *et al.* 2005: 576, see also Graham 2004 on ‘cognitive citizenship’). The CPCEC project identified a host of unquestioned practices that rest on unsupported assumptions about the minimal potential for communication by and with people with dementia. These practices have the outcome of excluding residents from even the most rudimentary participation in decisions affecting their lives.

In the absence of the level of personal knowledge of a resident that derives from a direct relationship, institutionalised care is organised around a symbolic order and system of values. With little space to reflect upon or question care practice, the staff maintain order in a manner that is at best only tenuously linked to the expressed needs of residents and at times directly antithetical to what are commonly considered the tenets of good-quality care: personalised support; the promotion and facilitation of independence and agency; and taking the presenting opportunities to maintain a resident’s sense of self and social identity.

Recommendations and conclusions

The ability to communicate relates only superficially to whether a person can participate in a conversation or respond appropriately to a line of questioning. Communication is the means by which people maintain interpersonal attachments. Such attachments underpin wellbeing and personhood. When a person is labelled ‘unable to communicate’ they are denied the right to a relationship with the world they inhabit. At present, the opportunity to engage meaningfully with others and maintain a social presence is incidental to the care and support on offer in dementia-care settings. As Bender and Cheston (1997: 523) observed, these are conditions

where the person with dementia has 'no place or permission to talk about themselves'. Indeed, residents are commonly assumed to be incapable of meaningful social interaction.

On the *context of care*, the interviews with care workers underlined how workload pressures shape care practice in an unwelcome fashion. The observations and filming revealed low overall levels of communication. It is difficult to escape the conclusion that higher staffing levels in dementia care would enhance the level and quality of communication between staff and residents. There is a need to review how this type of care is funded, the pay it attracts and how the staff ratio might better reflect the need to provide relationship-oriented care. The findings support the proposition that effective communication is crucial to the development of dementia care, but that *communication skills* are currently accorded a low priority and vary considerably from one worker to the next. This provides an argument for more formal recognition of these skills and competencies. The job descriptions for dementia-care staff should prioritise communication skills and reinforce the message that meaningful communication is a constituent element of dementia-care practice. The study has provided ample evidence of the need to create time and space for care workers to reflect upon and discuss communication whilst at work. The inspection framework might usefully include standards for staff support. During the interviews, the care workers struggled to articulate the communication skills they employed. Both training and work-place support for dementia-care staff could address this through development of a rich and elaborate discourse to represent and convey the detail of what is involved when effective communication takes place. There is a need for a new *lexicon of dementia care*.

In this gendered field of employment, the emotional dimension of dementia care is typically overlooked, and receives little in the way of formal support, but the *emotion work* of care staff is crucial to what they do, not least because it enhances and supports communication. It behoves care-providing organisations to recognise and to increase support for emotion work. Our findings indicate this has implications for the wellbeing of both staff and residents. The mundane tasks associated with daily living enjoy an inexplicable and overriding priority in dementia care. We were able to observe little else beyond these *routines of care* in the way of engagement and stimulation. Notable features of the conditions we observed included the absence of sustained periods of contact between staff and residents, and the scarcity of encounters during which residents were encouraged and supported in making an active contribution. These findings cross-cut different types of institutional care and demonstrate the importance of evaluating dementia care through attention to the level and quality of

communication. Many workers we spoke to indicated that prolonged periods of contact with residents were perceived as 'time-out' from work, yet many desired the opportunity to build relationships with the people they support. Such conditions provide grounds for re-evaluating the role of the dementia care worker in favour of an emphasis upon relationships over task completion.

The 'care-speak' mode of communication employed by care workers supports the everyday patterns of care. The corrosive impact of standardised interactions is largely overlooked as a result. There is a pressing need to provide care staff with the resources to challenge 'care-speak' and to develop a more situation-specific approach to communication. The *promotion and support of communication* in dementia care is for purposes beyond and quite separate from the efficient completion of tasks. Staff training needs to address communicative challenges and provide support in overcoming them. Such training must lift communication skills from the task-based culture of 'getting things done' to recognition of *why* maintaining relationships with people with dementia is crucial. There is a need to impress upon all who are involved in the care and support of people with dementia that meaningful communication is a fundamental right and requirement. Our findings suggest that an underlying comprehension of the rationale behind effective communication is not well established in residential care environments.

The filming and observation revealed the potential benefits of *relationships between residents*, but we observed a multitude of artificial barriers to maintaining such connections. Efforts to support communication in dementia care should extend beyond a narrow focus on staff-resident relations to facilitate the friendships and affiliations that people with dementia may offer one another, and to develop relations beyond care home walls. Our findings show that people with dementia can and should be consulted and included in the planning and provision of care. Their participation is a right that is currently denied to them, and this routine denial constitutes discrimination. We have outlined the benefits associated with structured attention to communication. This includes building a personalised communication record of residents based on repeated contacts and observations. Where more familiar channels of communication are problematic, alternative approaches to consultation should be integral to dementia care supported by recognition of *why inclusion is vital* to all care service users and the organisations that support them. Far from being a condition that erodes a person's capacity to communicate, we have found that dementia generates an array of creative responses from those affected by it, in an effort to connect meaningfully with others. Once this is accepted, doors open to new possibilities and a different story can be told.

Acknowledgements

The authors wish to thank the residents and staff of Jewish Care for their support and participation in the CPCEC project. We are also grateful to Bill Bytheway for his useful comments on an earlier draft of this paper and the two anonymous referees for their suggestions.

NOTES

- 1 For a more detailed review of research on dementia and communication see Ward *et al.* (2002 *a*, 2002 *b*).
- 2 The design of the project enabled the hypothesis to be tested, but the Director did not inform the research team of this until after the completion of fieldwork. The research team were blind to the hypothesis.
- 3 Schreiner *et al.* (2005) report making comparable modifications to the McCann (1997) observational tool.
- 4 Supporting the findings of a recent study that revealed homes registered as EMI and non-EMI offer a similar service (Reilly *et al.* 2006).
- 5 Thomas (1993: 663) has highlighted the importance of distinguishing between ‘the privately experienced emotional or feeling state of the person doing care work and the publicly expressed “emotional input” of the carer in the caring relationship’.
- 6 Michael is a pseudonym.
- 7 See Aggarwal *et al.* (2003) for a fuller discussion of this aspect of the project.

References

- Aggarwal, N., Vass, A. A., Minardi, H., Ward, R., Garfield, C. and Cybyk, B. 2003. People with dementia and their relatives: personal experiences of Alzheimer’s and of the provision of care. *Journal of Psychiatric and Mental Health*, **10**, 2, 187–97.
- Bender, M. and Cheston, R. 1997. Inhabitants of a lost kingdom: a model of the subjective experiences of dementia. *Ageing & Society*, **17**, 5, 513–29.
- Berg, A., Hallberg, I. R. and Norberg, A. 1998. Nurses’ reflections about dementia care, the patients, the care and themselves in their daily caregiving. *International Journal of Nursing Studies*, **35**, 5, 271–82.
- Bowie, P. and Mountain, G. 1993. Using direct observation to record the behaviour of long-stay patients with dementia. *International Journal of Geriatric Psychiatry*, **8**, 10, 857–64.
- Brooker, D. 1995. Looking at them looking at me: a review of observational studies in the quality of institutional care for elderly people with dementia. *Journal of Mental Health*, **4**, 2, 145–56.
- Butler, J. 1993. *Bodies that Matter: On the Discursive Limits of Sex*. Routledge, London.
- Coupland, N., Coupland, J., Giles, H. and Kenwood, K. 1988. Accommodating the elderly: invoking and extending a theory. *Language in Society*, **17**, 1, 1–41.
- Dean, R., Proudfoot, R. and Lindsay, J. 1993. The quality of interactions schedule (QUIS): development, reliability and uses in the evaluation of two domus units. *International Journal of Geriatric Psychiatry*, **8**, 819–26.
- Drew, P. and Heritage, J. 1992. Analyzing talk at work: an introduction. In Drew, P. and Heritage, J. (eds), *Talk at Work: Interaction in Institutional Settings*. Cambridge University Press, Cambridge, 3–65.

- Edberg, A. K., Sandgren, A. N. and Hallberg, I. R. 1995. Initiating and terminating verbal interaction between nurses and severely demented patients regarded as vocally disruptive. *Journal of Psychiatric and Mental Health Nursing*, **2**, 3, 159–67.
- Gilliard, J., Means, R., Beattie, A. and Daker-White, G. 2005. Dementia care in England and the social model of disability: lessons and issues. *Dementia*, **4**, 4, 571–86.
- Gilloran, A. J., McGlew, T., McKee, K., Roberston, A. and Wight, D. 1993. Measuring the quality of care in psychogeriatric wards. *Journal of Advanced Nursing*, **18**, 2, 269–75.
- Godlove, C., Richard, L. and Rodwell, G. 1982. *Time for Action: An Observational Study of Elderly People in Four Different Care Environments*. Joint Unit for Social Services Research, University of Sheffield, Sheffield.
- Goldsmith, M. 1996. *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. Jessica Kingsley, London.
- Graham, R. 2004. Cognitive citizenship: access to hip surgery for people with dementia. *Health*, **8**, 3, 295–310.
- Grainger, K., Atkinson, K. and Coupland, N. 1990. Responding to the elderly: troubles-talk in the caring context. In Giles, H., Coupland, N. and Wiemann, J. M. (eds), *Communication, Health and the Elderly*. University of Manchester Press, Manchester, UK.
- Hallberg, I. R., Norberg, A. and Eriksson, S. 1990. A comparison between the care of vocally disruptive patients and that of other residents at psychogeriatric wards. *Journal of Advanced Nursing*, **15**, 4, 410–6.
- Hallberg, I. R., Edberg, A-K., Nordmark, A., Johnsson, K. and Norberg, A. 1993. Daytime vocal activity in institutionalised severely demented patients identified as vocally disruptive by nurses. *International Journal of Geriatric Psychiatry*, **8**, 2, 155–64.
- Hamilton, H. E. 1994. *Conversations with an Alzheimer's Patient: An Interactional Sociolinguistic Study*. Cambridge University Press, Cambridge.
- Heritage, J. 1997. Conversation analysis and institutional talk: analysing data. In Silverman, D. (ed.), *Qualitative Research: Theory, Method and Practice*. Sage, London, 161–82.
- Hochschild, A. R. 1983. *The Managed Heart: Commercialization of Human Feeling*. University of California Press, Berkeley, California.
- Hubbard, G., Cook, A., Tester, S. and Downs, M. 2002. Beyond words: older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies*, **16**, 2, 155–67.
- Iwasiw, C. L. and Olson, J. K. 1995. Content analysis of non-professional caregiver-patient interactions in long-term care facilities. *Clinical Nursing Research*, **4**, 4, 411–24.
- Killick, J. and Allan, K. 2001. *Communication and the Care of People with Dementia*. Open University Press, Buckingham.
- Kitwood, T. 1997. *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.
- Kontos, P. 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society*, **24**, 6, 829–49.
- Lanceley, A. 1985. Use of controlling language in the rehabilitation of the elderly. *Journal of Advanced Nursing*, **10**, 2, 125–35.
- Lee-Treweek, G. 1997. Women, resistance and care: an ethnographic study of nursing auxiliary work. *Work, Employment and Society*, **11**, 1, 47–63.
- MacDonald, A. 2005. Care homes and dementia. *Aging and Mental Health*, **9**, 2, 91–2.
- MacDonald, A. and Dening, T. 2002. Dementia is being avoided in NHS and social care. *British Medical Journal*, **324**, 548.
- Marshall, M. 1994. Emerging Trends in Dementia Care: Some Thoughts on the Next Ten Years. Paper presented at Alzheimer's Disease International conference, Edinburgh, Scotland, 23rd September.

- McCann, J. J., Gilley, D. W., Herbert, L. E., Beckett, L. A. and Evans, D. A. 1997. Concordance between direct observation and staff rating of behavior in nursing home residents with Alzheimer's disease. *Journal of Gerontology: Psychological Sciences*, **52**, 2, P63–72.
- Nolan, M., Grant, G. and Nolan, J. 1995. Busy doing nothing: activity and interaction levels amongst differing populations of elderly patients. *Journal of Advanced Nursing*, **22**, 3, 528–38.
- Reed-Danahay, D. 2001. 'This is your home now': conceptualizing location and dislocation in a dementia unit. *Qualitative Research*, **1**, 1, 47–64.
- Reilly, S., Abendstern, M., Hughes, J., Challis, D., Venables, D. and Pedersen, I. 2006. Quality in long-term care homes for people with dementia: an assessment of specialist provision. *Ageing & Society*, **26**, 4, 649–68.
- Schreiner, A. S., Shiotani, H. and Yamamoto, E. 2005. Positive affect among nursing home residents with dementia: the effect of recreation therapy. *Journal of Aging and Mental Health*, **9**, 2, 129–34.
- Small, J. A., Geldart, K., Gutman, G. and Clarke Scott, M. A. 1998. The discourse of self in dementia. *Ageing & Society*, **18**, 3, 291–316.
- Thomas, C. 1993. De-constructing concepts of care. *Sociology*, **27**, 4, 649–69.
- Vass, A. A., Minardi, H., Ward, R., Aggarwal, N., Cybyk, B. and Garfield, C. 2003. Dementia of the Alzheimer's type: communication patterns and their consequences for effective care – ethical considerations. *Dementia*, **2**, 1, 21–48.
- Ward, R., Vass, A. A., Aggarwal, N., Cybyk, B. and Garfield, C. 2002 *a*. Communication and care. Part 1: Expanding our understanding. *Journal of Dementia Care*, **10**, 5, 33–6.
- Ward, R., Vass, A. A., Aggarwal, N., Cybyk, B. and Garfield, C. 2002 *b*. Communication and care. Part 2: Communication in context. *Journal of Dementia Care*, **10**, 6, 33–7.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C. and Cybyk, B. 2005. What is dementia care? Dementia is communication. *Journal of Dementia Care*, **13**, 6, 16–9.

Accepted 20 September 2007

Address for correspondence:

Richard Ward, Centre for the Older Person's Agenda,
Queen Margaret University Edinburgh,
Musselburgh, East Lothian EH21 6UU, Scotland.

Email: rward@qmu.ac.uk