Dementia care 1: person centred approaches help to promote effective communication

The Gold Standards Framework identifies good communication as a vital aspect of care. This study examines the strategies staff can use to improve their skills

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Background This first in a three part series on dementia care explores communication. The Gold Standards Framework includes a workstream on improving end of life care in care homes; communication is one of seven key tasks within the GSF.

Aim and method This study aimed to gather the views of care home staff on communication issues. Focus groups were conducted with 36 members of direct care staff from nine nursing and residential care homes. Results Three types of communication were identified: staff to staff, staff to resident, and staff to family. Discussion and conclusion The implications of different approaches to communication are discussed, and recommendations made for practice.

BACKGROUND The UK’s rising incidence of dementia means establishing good quality practice in care homes is paramount. The Gold Standards Framework (www.goldstandardsframework.nhs.uk), now part of the NHS End of Life Care Programme, has three main workstreams, one of which focuses on providing optimal end of life care in care homes. The GSF identified seven key tasks (known as “the 7 Cs”), the first of which is communication (Hansford and Meehan, 2007).

Around 1,000 homes have adopted the GSF (National Gold Standards Framework Centre, 2009), which is only a small percentage of all UK care homes. Furthermore, many articles highlight a lack of effective, in depth communication between staff and residents in care homes (Caron et al, 2005), as well as relatives’ dissatisfaction with care owing to poor communication (Engel et al, 2006).

AIM AND METHOD We wanted to gather the opinions and perspectives of care home staff on communication issues. We contacted 34 homes specialising in dementia care in the West Midlands. Nine formed the final sample – three were drawn from each of the following social services categories: privately owned by individuals (P), owned by a chain (C), and run by a charity/voluntarily (C/V).

Focus groups were conducted at each home with direct care staff, namely nurses, healthcare assistants and activities coordinators. They were facilitated by one researcher, tape recorded and transcribed. Managers participated if they wished. A total of 36 staff took part across the nine homes, with an average of four in each focus group (this ranged from 3–5).

Using thematic analysis, three types of communication were identified. Main themes are supported by staff quotations coded according to home number (1–9), type (P, C, or C/V), and participant number. As an example, home 9P is home number 9, which is privately owned.

RESULTS Staff to staff communication Handover meetings: all staff reported having handovers at change of shift – usually morning, afternoon and evening, which provided opportunities to review residents’ care and to update staff coming on duty about changes during the previous shift. While general handovers occurred in most homes, home 9P’s manager used a key worker system. Most handovers tended to be brief, reporting only pertinent information from the previous shift.

Exclusion of healthcare assistants: from staff comments, it is clear that some homes had strict role demarcation – managers felt separate from nurses, and nurses felt separate from healthcare assistants. This is a potential source of conflict – demarcation such as this appears to limit valuable communication between staff members about residents’ care:

“All respect to number 3 [manager], but she doesn’t work with us. We are on the floor 24–7 dealing with the residents… She doesn’t know what it’s really like” (home 4C/V, participant 1).

Other homes had separate handovers for nurses and healthcare assistants. One healthcare assistant from a home where such handovers were the norm said that if she wanted to raise a concern about a resident’s health/behaviour, standard practice was to note it on a “card index” for the nurses to discuss (home 7P, participant 3). In one third of homes, handovers involved the senior carers on duty only.

PRACTICE POINTS

- Care home staff should include healthcare assistants in care planning and decision making.
- They should ensure that good communication with residents is given the same priority as physical care needs.
- Staff should take advantage of every opportunity to interact with residents during routine tasks.
- Staff should use reminiscence to reinforce self identity and try to see each resident as a unique individual. This may enable them to understand challenging behaviour.
- Residents’ families should be involved in care planning and given appropriate information to help them make informed decisions.
Shared goals and team meetings: all staff reported good interaction and support among team members performing the same role. In some homes, although they had specific roles, staff felt part of a larger team with the shared goal of ensuring the provision of optimal care:

“We as trained nurses prescribe the care, so we have a 100% input into that, but numbers 3 and 4 [healthcare assistants] have 100% input into delivering that care” (home 9P, participant 2).

In home 9P, where each healthcare assistant was a key worker to six residents, the manager (a qualified nurse) valued their unique input when planning optimal care. Other homes involved every member of staff in care planning and decision making, holding weekly or monthly review meetings/case conferences. This reduces the potential for staff conflict by providing a forum for all to “discuss things in more depth and decide on how best to care for the residents” (home 6C/V, participant 4). Homes that reported conflict between carers and nurses (3C/V and 7P) had no full staff meetings so no opportunities for staff to raise concerns or decide on shared goals and practices, making collaborative working difficult.

Care staff comments suggest optimal care is facilitated when the staff team meet with each other, forge team values and shared goals, and where every team member’s contribution is valued. If this is done, staff experience job satisfaction and are able to draw strength and support from other team members.

Staff to resident communication
Talking while doing: many staff reiterated Kitwood’s (1997) view that good quality dementia care is based on positive interactions, where carers perceive people with dementia as “a person… focusing beyond the dementia” (home 6C/V, participant 4). Such “person centred” approaches (Stokes, 2000) “can really make a difference” (home 6C/V, participant 4).

Home 4C/V’s staff experienced greater job satisfaction when they took time to communicate with residents. However, fulfilling the job’s physical demands often curtailed communication opportunities: “You can’t always find the time, we are so busy” (4C/V, participant 1). Consequently, carers can sometimes become task orientated:

“We do absolutely everything for them, everything… you have the washing, cleaning and cooking to do” (home 8P, participant 1).

Where caring for residents’ physical needs outweighed their need for stimulation, staff became divorced from residents; one reported that the job ended up being frustrating (home 5C/V, participant 1). Such frustration can, in turn, agitate residents and aggravate the situation. Some staff were extremely inventive in creating opportunities for interaction while carrying out routine care needs:

“You can make anything into an activity, even when you are dressing them… picking up a picture and saying, ‘Oh, who’s this?’ and talking about that person” (home 3C, participant 3).

Opportunities for interacting with residents were seized; for example, while “walking with them, you talk about memories” (home 2C, participant 3). Home 3C had themed corridors to stimulate conversation/reminiscence:

“We have a movie corridor and it’s the old film stars. Residents sometimes go, ‘Ooohhh oooohhh oooohhh’, and you know… perhaps they can’t say ‘Oh, that’s Cary Grant’, but by the fact that they are ‘Ooohhh oooohhh oooohhh’-ing shows that there is something there. They do have a recognition” (participant 3).

Reminiscence: reminiscence is a key feature of staff to resident conversations. Staff recognised that stimulation and keeping old memories alive is important. This echoes Kitwood (1989), who found that some recovery of cognitive impairment and behavioural improvement (termed “remittance”) was possible, or at least the rate of deterioration may be slowed down when people with dementia are regularly engaged in reminiscence about their past.

Woods et al’s (2005) review on reminiscence found potentially beneficial effects, including significant improvement in CAPE (Clifton Assessment Procedures for the Elderly) Behavioural Rating Scale scores; caregiver strain was also significantly reduced. These findings support staff perceptions that reminiscence improves personhood, that is, helping staff to understand and value individuals and their general wellbeing.

Staff in home 2C were enthusiastic about daily “dementia individual sessions” (participant 3), and home 1C’s activities coordinator (participant 4) said that residents preferred “one to one” situations that provided opportunities to chat. Families were essential providers of details about residents’ social histories, hobbies and interests, which facilitate carer to resident interaction and inform care planning:

“If I want to involve a resident in reminiscence or discuss memories, I know their social history from the care plan, to talk about relevant things” (home 6C/V, participant 3).

Then “residents can really relate to the carer who looks after them and form a close relationship” (home 9P, participant 2), even having affectionate nicknames: “A couple of our residents call us by different names… like ‘Tinkerbell’” (home 9P, participant 2).

Social history information was integrated in “individualised activity programmes” (home 9P, participant 2) because:

“when [residents] have time to think, that’s when they start to get disoriented. So, if they are kept busy, they don’t have time to think and get upset” (home 6C/V, participant 3).

Home 6C/V’s activity coordinator highlighted the value of social history in providing possible clues to explain why residents displayed behaviour that staff perceived as challenging:

“We have a resident who used to be a carpenter, and he was messing with the hand rails, and he actually looked like he was sanding” (participant 2).

Rather than reprimanding him for stopping while walking to the dining room, staff now offer praise for a job well done. The more carers interact with residents, the more likely they are to see them as people, rather than as cognitively impaired owing to dementia. A healthcare assistant in home 4C/V was amazed to discover that one resident was a former member of the French Resistance. Revelations like this can alter staff perceptions of residents’ competency.

Empowerment: homes that adopt a person centred approach, where staff take time to understand their residents as individuals, make more effort to involve them in care planning. Home 6C/V held residents’ meetings once a fortnight, and ensured care plans were read and checked by each individual. Staff recognised that:

“Sometimes residents don’t have the capacity to fully understand what is being said to them, but we do try to do it when
they are most lucid and do it in stages, so they can comprehend” (home 6C/V, participant 4).

This approach confirms Spector and Orell’s (2006) findings that people with dementia, even in the later stages, remain capable of voicing opinions about their care and quality of life. As symptom severity increases, residents may be unable to vocalise their desires and concerns, but staff in homes that adopt a person centred approach become adept at interpreting residents’ non verbal communication.

Dismenpowerment: unfortunately, we heard evidence of staff “dismenpowering” (Kitwood, 1997) residents, especially where staff were task rather than person orientated, and had little time to form relationships with residents. In such cases, residents may display more behaviours perceived as challenging.

For example, participant 2 in home 5C/V referred to one resident as “Rambo” because of his aggressive behaviour and non compliance, while a healthcare assistant (participant 1) in home 8P referred to residents as “the rezzies”. Such disregard for individuals led to comments such as “they haven’t got a clue really” (home 7C, participant 3), and talk of “blackmail” to achieve compliance: “When you had chocolates, you could coax her [resident] to do things” (home 5C/V, participant 4).

Staff in homes using this approach described caring for residents as “mainly observation. We have set parameters and see how they are going on and if they meet their care plans” (home 1C, participant 3). This approach leads to staff, rather than residents, making decisions.

Reassurance and love: Kitwood (1997) argued that residents with dementia need stability and security, as they may be easily confused, upset and frightened. Home 2C’s staff gave constant reassurance, estimating they spent “90 odd per cent or so” of their working day reassuring residents (participant 2). Other staff reported using reassurance to calm residents displaying challenging behaviour. Home 8P’s manager said residents showed increased agitation during late afternoon, repeatedly saying they could stay no longer, as they had to return home to make dinner. Healthcare assistants relied on good communication skills to reassure residents.

In the majority of homes, staff considered that important care needs include residents “feel[ing] loved” (home 8P, participant 4), and being reassured “there is somebody there who cares for them” (home 6C/V, participant 3). Reassurance may be “just touching their hand or a hug sometimes” (home 6C/V, participant 3).

Residents with dementia may need comfort for several reasons, for example, because of bereavement or reduced ability to cope with daily living. At such times, the quality of communication between resident and carer is crucial in managing a difficult situation. Care staff in all homes raised the issue of managing questions such as “Where’s mum! Where’s dad!” (home 5C/V, participant 2). Staff dealt with these questions in a variety of ways.

Staff to family communication
Caron et al (2005) found relatives of people with dementia sought involvement in care discussions, especially when the illness worsened and required medical intervention. However, McCarthy et al (1997) found that 39% of relatives thought their questions did not receive in depth answers; staff preoccupation with daily routine tasks often interfered with such communication (Forbes et al, 2000).

Involving residents’ families: all staff emphasised that care homes were seen as residents’ homes and, as such, they operated an open door policy for family and friends:

“We encourage relatives to think of this as their home and make themselves feel at home as, after all, if mum or dad was living at home that’s what they would do, so we think it should just be the same here, as this is their parent’s home” (home 8P, participant 4).

In this extended family like context, staff and family enjoyed friendly exchanges. Staff commented that families tended to ask general questions about their relatives, to which they replied along the lines of:

“Oh, ‘they’ve ate well today’, or ‘your mum seems a bit tearful today’ or ‘your mum has had a really good day today’… basic information really” (home 5C/V, participant 1).

However, home 3C’s deputy manager warned healthcare assistants to “be careful what you say to the families”, knowing “they are quite vulnerable” (participant 3). Similarly, home 7P had experienced communication issues, hence only nurses were allowed to speak to family about residents’ health and medical decisions.

Homes 1C and 9P’s managers used key workers and named nurses to overcome communication issues.

Keeping family informed: all homes kept family members informed of residents’ health status and of any care plan or medication changes, to maintain openness:

“They [family] like to be kept up to date. In the past we have found that if we left it and didn’t call, they used to come in and say things like, ‘Oh, nobody has told me that my mum isn’t very well,’ so now it’s part of our policy to phone and let them know everything” (home 6C/V, participant 2).

Home 6C/V’s manager emphasised the importance of being approachable to family to safeguard staff from accusations or issues of accountability:

“Communication plays a big part with families. They would rather know that something has happened to the resident… rather than see them with a bruise or something and question what has happened to them” (participant 2).

Staff often went to great lengths to inform family of how residents are doing:

“[W]e send family letters home every month, and we just sort of update them about what has happened over the last month, and that includes activities, eating, sleeping, any changes in medication, falls and things” (home 2P, participant 3).

Email communication with overseas relatives was common, as staff in home 7P commented:

“We have one [relative] who lives in America, and he emails two or three times a week to see how his mum is. We read the emails out to her” (participant 1).

Family involvement in residents’ care: the majority of staff said that family were an invaluable source of social history and information to aid care planning, but relatives’ involvement in this varied dramatically between homes.

Home 1C’s families tended not to be involved with care planning, as “they are paying a lot of money. I think they would certainly be on our case if things weren’t right” (participant 1). This nurse felt the home was providing good quality care and residents’ families recognised this. Contrary
to Caron et al’s (2005) findings, participant 2 in home 1C believed “a lot of it [care planning] is irrelevant to relatives”.

Home 7P had invited family to attend “monthly reviews if they wish, but a lot of them really don’t wish to” (participant 5). To ensure attendance at the reviews, the home then required relatives to attend and was “asking people [relatives] to sign to say they attended the review on the care plan” (participant 5).

Home 1C’s staff believed that relatives’ lack of involvement was due to satisfaction with care provision, while 5C/V’s staff raised another possibility:

“One lady… her daughter said, ‘That’s not my mother. My mother died a long time ago’…” A lot of families say that” (participant 1).

Home 2C held monthly relatives’ meetings where “we get together and go through any deterioration or progress, and then we change that ISP [care plan] altogether” (participant 3); all families were involved in this process. Elsewhere, family meetings were less frequent: home 3C’s “reviews with the family would be with the social worker and unfortunately… that would be only once a year, but they have ‘relative/resident information sheets’” (participant 3) that families use to raise any issues.

Conflicting opinions: occasionally staff reported conflict with residents’ families over care issues, such as:

“We had a lady who had a poorly bottom and the family… insisted that we get this lady out and so I actually had to get involved myself, and say, ‘Professionally and in my opinion, this lady needs to be in a bed or we will never get this [pressure ulcer] healed.’ So I had to go against them basically, to say that she is here to be cared for and this is the way we need to care for her. I am sorry that you don’t like it, but…” (home 3C, participant 3).

Another potential source of conflict lay in relatives’ interpretation of staff comments/wording in care plan notes, and sometimes staff also found themselves caught up in conflict between family members:

“One family member knows that their mum’s got dementia, but the other one won’t accept it and says there is nothing wrong with her…. I don’t think the family are given enough information either ‘cos there’s one son in law who says that all the information he’s been given is off the internet, not off the doctor” (home 5C/V, participant 4).

Home 6C/V’s activities coordinator (a trained care assistant) addressed family members’ lack of knowledge about dementia by holding regular dementia awareness training sessions for family and friends. These provided families with opportunities to compare experiences. The manager at this home said this training was especially helpful to “a certain family who came in to us and when they saw their mum, she didn’t recognise them and they were totally in bits” (home 6C/V, participant 4). Staff in two homes emphasised that communication with relatives was a hallmark of the quality care they provided. While 1C’s staff believed relatives’ satisfaction with their expensive care accounted for their lack of involvement, staff at home 2C (which charged the highest fees) said all relatives had input into care planning. Home 4C/V, currently implementing the GSF, said:

“I think we spend more time with relatives in this home than many. That way, we don’t get so many complaints because we have built up a rapport with the relatives and they get satisfied with whatever we are giving their family member…. I would say that I would spend about 80% of my time… talking to them” (participant 3).

Home 4C/V appeared to benefit from GSF training by improving communication with all those involved in residents’ care. Effective communication between all parties can be achieved when residents and families are welcomed into the home, an open relationship is created, and family are told about dementia and medical issues, so they feel “they are contributing to the wellbeing” (Caron et al, 2005) of their loved one.

CONCLUSION

This study highlighted three main areas for care home practice to ensure residents with dementia receive the GSF’s standard of quality and continuity of care until death.

First, staff should empower residents by providing person centred care, and spending time interacting and getting to know residents as individuals. Opportunities for interaction include engaging in reminiscence, as well as making general conversation when carrying out everyday tasks. This empowers both residents and staff as their working environment becomes less stressful. Rather than being task focused, staff should relish opportunities for resident interaction to foster closer relationships. Second, staff should act as a team with the shared goal of optimal care provision. Each member (carers, nurses and managers) must feel appreciated and valued. Effective communication is crucial at and between all levels, to ensure a holistic approach to care. Finally, staff must recognise the key role of family, for example, in providing information about residents’ interests to inform care/activity plans, or social history that gives insight into the individual. Conflict with relatives is less likely to occur when they are informed about their loved one’s health status, are knowledgeable about dementia and are involved in decision making alongside staff.

Overall, our findings indicate that homes that adopt person centred approaches, and support, appreciate and empower staff, residents and relatives, achieve the GSF’s standard of optimal care. ♦

Part 2, to be published next week, explores medical and biopsychosocial approaches to dementia care

REFERENCES


