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Challenging care: the role and experience of Health Care Assistants in dementia wards

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The Report

1 First impressions: an introduction to the study

This section is presented as a preface to the report. After briefly describing the background to the study, it aims to orientate the reader to the material by summarising the process of engagement which the researchers underwent and sharing some of their initial accounts of the field.

1.1 Research design and methods

The approach used in this study of health care assistants (HCAs) was participant observation. The three researchers immersed themselves in the role of HCA; they put on the uniform and went through the standard job induction, which included training in lifting and handling and managing violence and aggression. They were then included on the staffing rota as supernumerary HCAs, experiencing all the shifts for three consecutive months, working more or less half time. They were deployed on different wards, but all three clinical settings treated older people with dementia and problematic behaviour. Throughout their time on the wards, the researchers kept a record of their experiences, making brief notes during their breaks on shift and writing up 'fieldnotes' when they were off duty.

Participant observation encourages researchers to reflect on their experiences and how they feel, as well as on what they see around them, so the fieldnotes contain not only a record of what they observed and did, but also how they felt. The researchers' guiding task was to explore the research questions about the HCA workforce: What motivates staff? What obstacles to good care do they face? What do they find stressful and how do they cope? What appears to promote staff wellbeing? What differences exist between different groups of staff (older or younger HCAs, male or female, ethnic majority or minority)? What are the implications of these findings for person-centred care, which is set as a standard of good practice? In this introduction to the research report, we invite the reader to share the researchers' initial responses to their role. The impressions given here introduce the concerns and reactions generated in the early stages of the research. They have been selected to familiarise the reader with the research setting, the methods adopted and some of the challenges tackled by the study.

To preserve anonymity, in the fieldnotes and interview extracts presented here, all ward staff have been assigned codenames. HCA codenames are preceded with H/ ; qualified nurses with Q/ ; ward managers and deputies with QM/ ; care environment coordinators with E/ ; and activities coordinators with A/. For patients and student nurses, [patient name] or

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[student nurse] is inserted into the text to replace real names. Where several patients are mentioned in one fieldnote, they are distinguished as [patient A], [patient B], and so on. Excerpts from fieldnotes and interview transcripts are included in separate, italicised paragraphs throughout the report.

1.2 A spy on the wall?

Before commenting on the researchers' initial reactions to the wards, we should explain the initial reactions of the other ward staff to the researchers:

H/AI said that, as I was supernumerary, I would not have that same 'it's my shift' stress. Others said that only three days a week was very easy, not a real experience of the job. I did not get the feeling that I was seen as a threat. I adopted a learner identity which helps with this. A few asked what I was interested in and I tried to pitch as voicing their experiences, stresses, joys etc... (Fieldnote, Ward B)

The staff being studied were fully aware of the risks which might be encountered if the results reflected unfavourably on them:

After I had explained my role, QM/AG made a comparison to a television documentary a year previously where a researcher had entered a nursing home as a HCA to demonstrate the quality of care in nursing homes. This programme had shown bad practice and nurses expressed their disapproval of the 'goings on' in that home. H/HA said: 'So, you're a spy on the wall then are you?' (Fieldnote, Ward C)

1.3 You get used to it

The researchers' first impressions of the wards might be shared by anyone who comes to work as an HCA:

One of two new patients today, a lady who had been moved from a nursing home for aggressive behaviour and confusion, suddenly got extremely upset and angry and headed out of the dayroom with her walking frame looking for the door. H/HA advised me to stay where I was as the more people who surrounded her, the more upset she would get. From the dayroom we could hear her down the corridor shouting and hitting various doors and walls with her walking frame. She was in the corridor for about an hour where [student nurse] attempted to calm her down and the staff nurse, Q/NI tried to give her some medication to calm her down – of which she refused. H/HA said Q/NI was usually quite good getting it down them, but today, she said [patient name] was just too agitated. Shortly after Q/NI had left the dayroom with the medication, Q/NI came and told us that [patient name] wouldn't have it and that she was too wound up. Q/NI said that she would leave her, H/HA replying that the more people there the worse she would be. The noise from the corridor was causing some of the other patients to become a little tense and we reassured them it was alright, saying it was just someone getting a bit upset. I asked H/HA if staff just get used to dealing with patients like this, and if it just becomes normality eventually.

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She said 'Yes, you get used to it – we've had worse than her'. (Fieldnote, Ward C)

The researcher's observation confirms that the setting was unfamiliar and somewhat frightening. The fear may have been compounded by the impotence felt by a newcomer who was told firmly not to get involved. The fieldnote continues with an aside on the part of the researcher:

I could not imagine there being a 'worse' case than this. I had never heard anything like it before and would be quite happy if I never heard it again. After today's shift I was again left with an awful headache which began to lift on returning home. I will certainly be packing painkillers for my next shift. (Fieldnote, Ward C)

Such apprehension might well be shared by any patient in times of lucidity on the ward, or by visitors, as well as staff. After spending a few weeks on the ward, however, the researchers noted that many aspects which had initially surprised them came to be accepted as routine. At the outset, for example, providing intimate personal care was a challenge, as it would be for any novice carer:

The hardest part was witnessing how painful the 'toileting' experience is for the patients. [Patient name] in particular, who smiled quite sweetly as we walked down the hall together, began to really panic as soon as we were in the bathroom and she realised that someone was removing her underthings. She gripped my hand more tightly as she began to lash out at H/WN with her other arm, shouting 'no, no, no, I don't know, I don't know, no!' and then calling out the names of various people in turn, as if to be rescued… The other HCAs are all very professional and courteous and keen to protect privacy and dignity as much as they can, but as an outsider the whole thing feels so invasive. (Fieldnote, Ward A)

Nevertheless, the researchers found that they grew accustomed to providing personal care, and that indifference to these tasks was an essential qualification for acceptance from the other HCAs, since the HCAs referred in a disparaging way to those they considered squeamish, such as 'certain qualified nurses'. In relatively little time, the researcher quoted above ceased to feel like 'an outsider' or to comment on the 'invasive' aspect of taking an adult to the toilet.

1.4 Routines and satisfactions

As all three researchers established themselves as members of the HCA team, their perspective came to incorporate not only their own personal experience but also the object of the study, the other HCAs, and they began to appraise the work in hand:

H/WL is the one who impressed me the most today … her skills with the patients are what I came to see (as it were). I'm thinking particularly of the way she handled [patient name] in the toilet – she managed to establish the limits of acceptable behaviour ('no, <u>don't</u> shout at us like that, that's <u>not</u> okay'), calm her down, restore her dignity to the extent possible, and gently

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take care of business all at the same time – after about 12 hours on the job and not much of a break, as far as I could tell. She jokes when it's okay, speaks calmly when that's better, and proceeds more gently and sweetly than I would have thought possible of her when unsure (like with the new patient today). (Fieldnote, Ward A)

Not all the researchers' observations reflect incidents of drama or conflict; they also recorded routine activities and their ongoing adaptation to the day-to-day demands of their working environment. These daily routines and the impressions they gave the observers illustrate the everyday tasks undertaken by HCAs:

Perhaps I had some rose-tinted perspective today but my combined experiences this morning with [three patients] – almost whoever I had talked to or worked with had seemed happy. It filled me with this real sense of satisfaction and belonging. I wonder how much of it was down to the fact that we were about one staff for every two patients – plus the two students, who are both really good. All patients were obviously getting plenty of attention. (Fieldnote, Ward B)

The time and energy which can be taken up in simply giving attention to people with dementia are illustrated in the following fieldnote:

Spent almost this entire time tending to [patient name], who has been very restless today. I think she may have been a cleaner in the past because she occupies herself by moving furniture round, cleaning around it and wiping the floor etc. With the incident earlier there was a bit of tiptoeing around her. I initially took some food down to her room, however she was in the bathroom on her own with no trousers on. With the aid of H/AI and Q/OA, we managed to get her back into her room and trousers back on. Then Q/OA brought her medication out which was fed to her with ice cream. She seemed quite happy with this and H/DY was openly telling her that they were tablets they were feeding her. I was then left with her to try and encourage her to eat the rest of her food. This proved quite difficult because of her continued inattention to her food and restlessness to go and tend to the dirt which she could see everywhere. She got up at one point and I noticed she only had one sock on, so finding the other sock I spent the next 10 minutes or so trying to persuade her off the floor she was wiping with her hand to let me put her sock back on. The whole time she was being very smiley and pleasant, but not agreeing to sit. Eventually I got her back on the sofa with her food on her lap and her sock back on her foot. She managed a reasonable amount of food and some tea. When I came to take the plastic apron off I had a big line of sweat along the hem – they are pretty unpleasant things to wear. (Fieldnote, Ward B)

Although some of the trials of the job were evident from the outset of the study, the researchers were attentive to the satisfactions as well. They observed demonstrations of warmth and affection between staff and patients, interludes which emerged as among the most rewarding aspects of the work:

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I was standing by the dividing half-wall with H/CE and H/BN when [patient name] shuffled up looking incredibly sad, which is her habitual expression. H/CE immediately turned to her and enfolded her in his arms, and stood there hugging her while he talked to us over the top of her head. 'This one is one of my favourites,' he said. 'Top ten. Maybe even top five'. Then he and H/BN reminisced about H/CE's favourite patient of all time, laughing about this old gentleman's sense of humour and about something in particular he once said. (Fieldnote, Ward A)

For the unproblematic sleepers, putting to bed is a really nice time. They are often clearly happy about going to bed and there is something in the nature of the activity which promotes attachment between patient and staff. I commented on this at some point and H/AI agreed, saying she enjoyed making people comfortable and having a cuddle or kiss goodnight. (Fieldnote, Ward B)

E/AA was sitting at the computer in the office when [patient name] appeared at the door behind her and started massaging her shoulders. E/AA made some comment like 'ooh that's lovely' – she obviously assumed it was a staff member, and we all waited for her to look up and realise, which she did with a little yelp and a laugh – which sent the whole office into peals of laughter. 'Tell them all to shut up' said [patient name]. 'Yeah!' said E/AA, giving [patient name]'s hand a stroke as he continued to rub her shoulders. (Fieldnote, Ward B)

Incidents of this kind highlight the humanity of the people with dementia on the wards. They illustrate the bonds between HCAs and those in their care, demonstrating the HCAs' appreciation of patients' individuality.

1.5 Stress and coping

By contrast, the fieldnotes present the wards as often busy, sometimes fraught and noisy settings, in which the individuality of the patients can become obscured. Empathising with the HCAs as they reflected on their own physical and emotional reactions to such settings, the researchers identified stressful aspects of the job early on in their observations:

There were so many moments today which felt stressful, with the result being that I feel a combination of jumpy and exhausted now. There was [patient A], wandering into other patients' personal space, trying to remove their chairs or slippers or feet – and then becoming agitated – and me panicking that at any moment one would lash out at the other. There was [patient B] who kept crying and moaning, and [patient C] who peed all over himself, the chair and the floor while at the dinner table … and [patient D] who scares me silly, I think because she seems too cognisant … but unpredictable and volatile. There was [patient E] who's too young … just does not understand what he's doing here. And then the ones who are so sweet and lovely – like [patient F] – that I almost can't bear it, it breaks my heart to walk away from them. And the feisty ones like [patient G and patient H], who are better at making jokes than I'll ever be. How do the staff switch this all off? (Fieldnote, Ward A)

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The approach taken in this study enabled us to answer this question fairly comprehensively, both from the researchers' own experience and from the observations and interviews they conducted. Later in this report, we look in some detail at how HCAs manage the stressful aspects of the work. The sources of stress are many, including emotional demands made by patients and risks of violence, as well as the constant exertion of physical caring:

Several minutes later, H/AM and I were coming out of the toilet with another patient when H/HN came down the hall toward us, pushing [patient name] in her wheelchair and saying with an edge in her voice 'don't ask me to do things I can't do, [patient name]'. Then H/HN looked up, caught our eye, and mimed dropping a hatchet on the top of [patient name]'s head. 'Wanting me to put her out of her misery, shoot her in the head…' she said as she pushed the wheelchair past us. (Fieldnote, Ward A)

During handover I noticed the nervous looks on the students' faces and one or two looked positively terrified – especially when Q/AG spoke of a new patient who had become increasingly aggressive at home and had threatened to kill her neighbours and their families. One of the students' eyes widened and all three of the glanced at each other, staring back to the floor shortly after. In contrast, the nurses and HCAs present did not react to this with the terrified looks but with raised eye brows and smiles as they listened to Q/AG, who had soon moved onto the next patient. (Fieldnote, Ward C)

As the setting became more familiar, it also became less frightening. For the researchers, the process of familiarisation involved getting to know the patients and their personalities, and becoming useful through assisting in the ward routine:

Lunch served from hatch in corner of main room. I fed [patient A], who was chosen for me because very easy to feed. First hands-on thing I did, felt very good. Afternoon continued to stay mostly in main room with [patients B, C, D, E, F and G] – who has fantastic sarcastic sense of humour. [Patient E] also quite good communicator. [Patient G] kept trying to grab my tea – became bit of a game. Later [patient G] had a clash with [patient H] when he tried to eat the playing cards. [Patient D] was taken into a separate room for fear of spitting near [patient G]. [Patient D] hasn't spoken to yet, had a stomach-ache this morning and was asleep most of afternoon, sounds like he still has quite good speech. [Patient E] seems to like to move around a lot – she managed to get into the CPS office this morning and set off an emergency alarm – regular prank apparently. (Fieldnote, Ward B)

This excerpt shows how behaviour which would be unacceptable in other social settings came to be regarded by the researcher as unsurprising. Such behaviour was reframed as a 'game' or 'prank', one mechanism which appeared to aid staff desensitisation and minimise the patients' responsibility for actions which are sometimes classed together as 'challenging behaviour'.

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1.6 Learning from colleagues

Since the researchers were inexperienced in the work, they learned a lot about the job directly from the experienced HCAs. Some colleagues proved less forthcoming than others, which may be due to reservations about the purpose of the research. The researchers acquired different types of knowledge about being HCAs from their colleagues on the ward. First, there was practical information, imparted by instruction and by example:

She told me Q/LO often had problems getting them to take their medications, or getting them to have a drink if they were refusing or were dehydrated. H/HA said that if you sit calmly with patients and try again after five minutes they'll often agree. She said it's about building up trust and not springing it on them, expecting them to know what it is you're offering and recognise the activity straight away. (Fieldnote, Ward C)

It is interesting that the 'correct' approach to giving medication was described by an HCA, by comparison with the qualified nurse's difficulty in doing so. This illustrates the implicit positioning of HCAs against other professionals, which was also made explicit by some colleagues, who presented the HCA role as inherently undesirable:

H/HA told me that we are the 'dog's bodies'; we do most things the nurses do, but all the extra dog's body tasks that no one wants to do. (Fieldnote, Ward C)

Staff also shared with the newcomers the group norms for the workplace. These included, for example, the ritual of making tea for each other, which caused the researchers some embarrassment in the early days when their inadequacies in this regard were a source of teasing. In its own right, however, teasing demonstrated a measure of acceptance and integration into the team.

1.7 Response to aggression

A strong lead was given by experienced HCAs with respect to the 'normal' response to verbal abuse or physical aggression from patients who are cognitively impaired. Minor infringements of social etiquette were generally a source of amusement:

[Patient name] was given her tablets and told Q/OA in her broad Nottingham accent to 'shove 'em up yer arse', which prompted laughter from all the staff. (Fieldnote, Ward B)

From the researchers' notes, pinching, hitting, spitting and kicking were common. This aspect of the setting surprised all the non-clinical members of the research team.

Quite quickly, [patient name] became upset again – lurching to her feet and grabbing hold of my wrist, she dug her fingernails in while roaring up at me. Although I managed to prise open her grasp and settle her back in the chair, the same thing happened again quite quickly. When H/AN returned, thankfully, I was able to examine the damage – finding that she'd dug long

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scratches into the skin on my right wrist and forearm, breaking the skin in about five places. … H/AN made the only comment about the scratches when she said to H/SN, 'she's a real HCA now!' (Fieldnote, Ward A)

There was a clear message that physical pain and possible scars are an intrinsic part of the job, that an HCA must expect these and should not make a fuss. Even when more grievous injuries led to significant physical and psychological damage, the team appeared to deal with the consequences without recourse to outside help:

The worst part of the job, they said, was the physical risks involved. H/BC talked about the two times that she has been injured quite badly by a patient, both several years ago – and how difficult it was 'to walk back through the door of the ward', to face the patients again. When I asked how staff cope with that, H/PN said they worked together to watch out for and protect each other. 'She'll say, "I'll go and get so-and-so up", and one of us will step in to say "no, you're all right, I'll do them" – you know, to protect her, so that she doesn't have to work with that patient again'. (Fieldnote, Ward A)

Despite the HCAs' stoical approach, the physical and emotional implications of the work are key features of the research environment which require highlighting in our analyses. HCAs are exposed daily to the risk of verbal and physical aggression from the people for whom they care.

1.8 Conclusion: setting the scene

It is important not to lose these first impressions from the researchers who produced the data for this study. They are presented here as a starting point for reading the sections which follow, representing what any new member of staff, patient or visitor to the ward might well experience. These first impressions set the scene for our analysis by portraying the research context as it appears to a fresh eye, before its features become so familiar that they are no longer recognised or noted; in other words, before the onlooker or reader becomes desensitised to the particularly painful and distressing features of the study context.

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2 Why look at inpatient dementia care?

As people live longer, the number of people affected by dementia grows and their physical health also declines. As a result, there is an increasing need for specialist dementia care in hospital settings. In Britain, one in four adults aged 70 to 74 living in private households shows some cognitive impairment (1), and the proportion increases with age. An estimated 700,000 people are now living with dementia and this number is expected to double to 1.4 million within the next 30 years as the population ages (2). While the private sector plays a major role in providing continuing care for people with dementia in advanced stages of the illness, National Health Service (NHS) inpatient dementia wards are the last resort of patients with high levels of behavioural disturbance and psychological distress.

The National Service Framework for Older People (NSFOP) stated that hospital-based services provided by specialist mental health services should include acute admission and rehabilitation beds, and that there may be separate facilities for patients with dementia and those with other mental health problems (3). While the care of people with dementia is meant to take place mainly in community settings and the intention is that people should remain at home as far as possible, entering long-term care as a last resort, sometimes hospital care is used to assess and treat co-morbid mental health problems such as depression or anxiety, or to ameliorate behaviours which are difficult to manage in domestic settings such as sexual disinhibition or acts which appear aggressive.

In addition to the relatively small numbers of patients admitted *because* of their cognitive impairment and associated symptoms, a significant number of older people receiving care in acute hospital settings are likely to also have dementia. A survey in Lincolnshire estimated that 12 percent of hospital inpatients have dementia (4). An increasing number of health professionals therefore find themselves caring for people with dementia and other mental health problems in hospital settings.

People with dementia present particular challenges to the nursing ideal of personalised care. This ideal requires health care staff to understand a person's subjective state and respond appropriately (5). However, a person with dementia may not be able to communicate clearly or to give an account of his or her history and preferences, and emotional responses may be unpredictable.

It is difficult for health care workers to treat patients with dementia, isolated from their normal environments and social circles, as individuals. Given the pressures of time and risk management, dementia wards may be kept locked and patient choice may be limited. Attention to basic physical needs may distract from the emotional dimension of caring, and impersonal routines may dominate the care process. This tendency has been attributed to a managerial approach to caring which emphasises the physical over

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emotional aspects of care. For instance, Kontos *et al* (6) argue that '[t]he rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction, militating against the individualising of care and the development of relationships between care provider and recipient that is central to a person-centred approach to dementia care'. Such circumstances are known to generate the deleterious manifestations of institutionalisation, whereby routines become regimented and systems override personal choice – with ill effects on staff and patients alike.

An example of the consequences that can follow is illustrated by the Commission for Health Improvement enquiry into Rowan Ward, which found that problems arose from low staffing levels, lack of training and lack of nursing leadership, together with isolation and lack of clinical governance. The subsequent review of older people's mental health services again highlighted the importance of recruitment and retention of skilled and motivated permanent staff (7).

In February 2009, the UK Department of Health released *Living Well With Dementia*, a comprehensive national strategy for improving local provision of 'good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals, and in care homes' (2). With this landmark document, England joined five other countries (Norway, France, Scotland, Australia, and South Korea) in making dementia a national policy priority. Funded for £150 million over the first two years, the strategy is designed to cross the boundaries between health, social care, and the third sector, and to unite service providers, people with dementia, and their carers in pursuing three broad goals: raising awareness and understanding; promoting early diagnosis and support; and improving conditions for those living with dementia.

Objective 13 of the *National Dementia Strategy* relates directly to the current study in specifying that the staff involved in caring for people with dementia must be equipped, through basic training as well as continuing professional and vocational development, with the 'right attributes and skills' to provide the best quality of care in the roles and settings where they work (2). The strategy explicitly links patient outcomes to investment in staff, staff morale and motivation, and team longevity and effectiveness.

2.1 Relevant research

While nurse-patient interaction has been studied extensively using qualitative methods (8, 9) and nursing has been studied in general (10), little attention has been paid to the particular psychological and social aspects of working in inpatient Mental Health Services for Older People (MHSOP). However, intensive care nursing – which is an analogous environment in some ways – *has* come under scrutiny. Chapman (8) found that social support was important in alleviating stress among intensive care nurses, and Badger (10) identified a range of coping strategies applied by nurses in a medical intensive care unit. Coping techniques which were deemed to be 'adaptive' included: cheerful denial, business-like manners

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(isolation), passive withdrawal, humour, and (occasional) anger. Use of faith, existential beliefs and mutual support were advocated in interviews but more difficult to observe. 'Maladaptive' techniques included: avoiding the patient, emotional withdrawal, fostering overdependence, acting out (calling in sick, coming in late), focusing on technical aspects, denying all feelings, and over-treating the patient. We expected a similar array of coping techniques to be found in MHSOP.

In contrast to previous research, the focus of our study was Health Care Assistants (HCAs) who provide most of the hands-on care in MHSOP. This is equivalent to the role of nurse's aides in the United States. We were unaware of any previous research which looked at HCAs' experiences and, moreover, our enquiry was broader than previous audits of coping techniques. In her analysis of 'caring', James (11) stresses that it is the 'minutiae of daily living', such as eating, sleeping, and personal hygiene, which largely determine quality of life for care recipients. As the primary providers of direct nonmedical care on the wards, HCAs can therefore be seen as the main arbiters of their patients' quality of life.

2.2 Background to the present study

The aim of the present study was to understand the experiences of staff working directly with older people with dementia. We focused particularly on HCAs for three reasons: they are a staff group about whom little research has been done; their hands-on role in providing routine personal care is clearly crucial to the quality of the patient experience; and they are regarded by an informed public as an important element in the organisation of care. In workshops conducted by Sheldon (12) as part of a scoping study to investigate the relationships between staff morale, workforce issues and the organisation and delivery of health care, people 'placed most emphasis on the use and training of HCAs and other support staff (including both housekeepers and ward clerks)'.

We therefore set out to lay some conceptual foundations on which to build a body of empirical knowledge in this under-researched field. A guiding question was what motivates staff working in this area, rather than other health care settings which might appear to offer more satisfying patient-carer relationships. We began with an understanding that providing inpatient mental health services for older people is in many ways problematic, particularly in relation to people with dementia. Quite apart from the difficulty of establishing the relationships which are a necessary condition of person-centred care (see Sections 6.4 and 6.5 on person-centred and relationship-centred care), the job contains a number of inherent contradictions. For instance, in MHSOP cures are generally not expected yet end-of-life care is seldom mentioned in the literature. The ethos of care in most hospital settings is rehabilitative, yet staff on inpatient dementia wards are generally aware that their patients are unlikely to return home. In contrast to most health settings, there are high levels of behavioural problems on dementia care wards, including violence and aggression, and patients are rarely in a position to express gratitude or

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appreciation for the efforts of staff. Consequently, the physical demands of the job as well as its emotional impact are high, while the system within which the ward is functioning seems geared up for different outcomes in some respects.

2.3 Research design

The use of participant observation and grounded theory in health care settings is not unusual (13-15). In these recent examples, data from observations are typically triangulated with other sources of information, including health care records and interviews, to achieve a full understanding of a given setting or process. The present study follows this tradition. It is unusual, however, in that three settings were observed at the same time, and the data were jointly analysed by the research team.

The data were gathered by three qualified researchers, each working in a different ward for older people with dementia in the same Trust. The three sites varied in several respects. One ward was located in a large teaching hospital in an urban setting (25 beds, reduced to 20 after the end of the project period). The second was a purpose-built ward at another site in the same city (13 beds). The third was in a community hospital in a small, former mining town (13 beds). This diversity and the consensus achieved through a team approach to data analysis contribute to the generalisability of our findings to other settings.

Access to the research settings was facilitated by the participation of the local MHSOP managers who participated in drawing up the study proposal. With authorisation from senior staff, the principal investigator (PI) prepared the wards for the arrival of the researchers by visiting each ward several times, timing these visits to enable most staff to have an opportunity to hear about the study, ask questions, and receive written details.

The research team was recruited jointly by the PI and the three ward managers, to ensure that the successful applicants were suitable for employment as HCAs as well as being well-equipped academically for the role of ethnographer. During their first few weeks on the wards, the researchers completed a four-day NHS Trust induction which provided information on basic life support, back care, food and hygiene, fire safety and safeguarding vulnerable adults. They also took part in a two-day course on managing violence and aggression (MVA) which covered the theory and practice of de-escalation and safe breakaway. Working approximately half-time, the researchers were then included on the rota as supernumerary staff, covering all shifts (as described in Section 3.2: *Job terms and conditions*).

Project advisory group

The Project Advisory Group for this study was made up of clinicians in old age psychiatry, managers from the Trust concerned, a workforce development representative, academics with experience of qualitative, applied healthcare research and two senior nurses with extensive experience of dementia care. Chaired by a former clinical director of the

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Trust in which the research took place, this group met five times in the course of the study to receive an account of progress and to offer advice on matters arising. Members of the group also participated in the recruitment of the researchers, their induction to the health service, training in qualitative methods, periodic mentoring of each researcher and consultations on the data analysis. Academic members advised on the peer-reviewed publications arising from the study.

2.4 Data collection and analysis

Working part-time as HCAs, the researchers participated in the life of the wards for three months while recording their observations in extensive fieldnotes. The team spent the next three months analysing this data, then each researcher returned to his or her ward for a further month to validate the findings. Following this, the researchers interviewed staff individually and in focus groups over a two-month period.

The fieldnotes and interview scripts were transcribed and coded in NVivo 8 for analysis. To indicate the volume of work this entailed, the researchers' fieldnotes amounted to 800 pages, 313,000 words altogether. The 30 interviews and five focus-group transcripts amounted to a further 242,000 words, for a total of 555,000 words.

We commissioned Dementia Care Mapping data from each study site to give us an independent assessment of life on the wards. The mapping was done by trained and experienced mappers and analysed by a member of the Project Advisory Group. This was a contribution in kind to the study from the host Trust. The mapping informed our analysis but the results are not presented here to protect the wards' anonymity.

Two focus groups with informal carers for people with dementia were facilitated by the local Alzheimer's Society, to contribute a carers' perspective to our analysis of the preliminary findings. Many of the carers had experience of bringing the person for whom they cared to similar wards. These focus groups offered a different perspective on our data, generating issues which would not otherwise have come up and helping shape the questions posed in the subsequent staff interviews and focus groups. While interpretation of data from these focus groups is complicated by the fact that often the wards to which the participants referred were not those which we were observing, nevertheless the focus groups raised our awareness family carers' interaction with people – many of them HCAs, who are paid to care for a person with dementia. Carers shared positive and negative experiences of care staff in day centres, nursing homes and hospital wards, and discussed in depth the importance of training, with specific recommendations for the content of dementia training.

We deviated from our original research design in two respects. We only had enough participants for one focus group per ward, not three as anticipated, and the carers' questionnaire which we intended to analyse as routinely-collected data was not in use on all the wards. Since carers were not the

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object of our observations, this was not a grave loss. The distribution of interviews and focus groups is shown in Table 1.

Table 1. Interview and focus-group data

Ward A		**B**	**C**
HCA interviews	8	4	3
QN interviews	6	2	2
Other staff interviews	2	2	1
Focus group	1	1	1

The data analysis was led by the researchers, and there were several points in the process when the people whom we were observing had opportunities to validate observations or challenge inferences drawn. In the period between the two data-collection phases, *a priori* themes were identified by the researchers using a grounded theory approach. Sub-themes and related topics were linked to these major themes in a tree-diagram or 'memo' format. The memos constructed in this way are listed in the Table 2 below.

The most substantial memos were discussed with the PI, who had read the fieldnotes, and selected memos were shared with the Project Advisory Group. These discussions were used to identify key issues in relation to the study questions.

The key themes and questions arising from our preliminary discussions formed the basis of the semi-structured interview schedule and focus-group guides for the second phase of data collection. Through these interviews and focus groups, the participants (nurses, HCAs and a couple of activities organisers) were exposed to the issues which the research team had generated. They were invited to respond to our first impressions both in the individual interviews and as a group. This process of feedback, validation and reflection helped the research team to test out our initial inferences, and to explore exceptional cases or apparent contradictions. Most importantly, it gave a voice to our research participants: we learned about their motivations, experiences, attitudes and aspirations.

The interview process was unusual in that the interviewer was known to the interviewee, but had changed roles from colleague to researcher. Despite the fact that the researchers no longer wore the HCA uniform when conducting interviews, we found that the trust established on the basis of shared experience over the preceding months of working together contributed to the quality of the interview and staff focus-group data. In this regard, the second phase of data collection was explicitly participatory, through the mutual exchange of knowledge.

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Table 2. Memo topics

- Acceptance
- Attachment
- Challenging behaviour
- Cigarettes and alcohol
- Communication with patients
- Detachment
- Family/friends of patients
- Identity management: Us versus them
- Individual in role
- Job-life interface
- Methods and approaches
- Patient management
- Person-centred care
- Relationship to 'management'
- Resources
- Rota
- Routine
- Shift characterisation
- Skills
- Staff relationships
- Suitability of patients
- The team

To the extent that the interviews facilitated joint reflection, the approach to data collection and analysis may be described as 'critical ethnography', which emphasises reflection on the part of researchers as well as on the part of those being researched (16, 17). In critical ethnography, the group or individuals being studied are often marginalised and the approach seeks to explore how they perceive their disempowerment; whether they are actually aware of it; and how they respond to such positioning (18). Aspects of the present study which are characteristic of critical ethnography include the researchers' reflections on their roles and the impact they

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themselves had on the research settings; the interviews and focus groups described above, which involved 30 individuals out of a possible 78; and also the participation of some of the ward staff in feedback sessions with the research team. In the latter, our summary findings were presented to a cross-section of staff to invite their comments and some adjustments were made as a result. While we did not overcome the staff's reticence sufficiently to claim that the present report constitutes a thoroughgoing critical ethnography, the fieldnotes have the potential for further analysis from the perspective of the HCAs observed.

Five feedback sessions were held, near the study sites, at the end of the second phase of data collection, each scheduled around handover time to permit as many people as possible to attend. Although invitations were issued by the known researcher, with reinforcement from the ward managers and general manager, only 12 staff members in total, among them only five HCAs, managed to attend these feedback sessions. Because this number was worryingly low, at the recommendation of the Project Advisory Group, the PI visited the ward managers individually a month later to check whether any residual issues had been brought up by the staff and to hear if the ward manager wished to make any further comments.

During these visits, the ward managers asserted that our portrayal of life on the wards corresponded to their experience. They found few surprises in the summary findings presented so far, but they understood the importance of making their own implicit knowledge available to a wider audience. The managers praised the individual researchers' contributions to ward life and would be glad to employ them again if the occasion arose. The only source of discomfort was the managers' awareness that the researchers' salaries were considerably greater than the pay of the other HCAs; one manager felt that if this inequality were disclosed, it could be a source of dissatisfaction among the staff. Otherwise, they assured us that the experience was positive and that they would be glad to participate in future research opportunities. While we cannot be certain that all 78 ward staff, including 42 HCAs, would wholeheartedly agree with this, we have not been approached by any dissenting individual, despite repeated invitations to all to make comments by any means of communication. We therefore conclude that the research process, which at the outset posed complex ethical and practical challenges, on balance proved acceptable and even constructive for the participating wards.

2.5 A brief note on limitations

The constraints and limitations of the approach to data collection taken in this study should be acknowledged. The adoption of the role of HCA by the researchers was designed to give them access to an unfamiliar world-view, and to lead to a greater understanding of this world, from which to address the study questions. This necessarily excluded other perspectives: direct-care staff other than HCAs (nurses and activity co-ordinators) were observed, but the researchers did not participate in those roles, and other healthcare staff are hardly evident at all in the fieldnotes. The impact of the

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researchers on the study setting is something which we portray in the first chapter. This was overt participant observation, insofar as all concerned knew who the researchers were, and why they were there. This introduces the possibility that the experiences of the researchers were manipulated in some way by the other staff or carers on the ward, to give a false impression. Image management is only to be expected when individuals or a group are being observed by an outsider. The study design countered the inevitable effects of this phenomenon in two important ways. First, the sites were discrete and it would have been impossible for all three to collude in managing the researchers' impressions. Second, we conducted 30 confidential, individual interviews, which invited the subjects to comment on inconsistencies between our inferences and their experience. The data from these interviews helped us to make our conclusions more comprehensive, incorporating individual exceptions to the generalities which we had observed.

A further caveat should be noted here, which is the danger of participant observers 'going native', ceasing to reflect from an observer's vantage point and adopting the world view of the people being studied. This could lead to biased results. For example, in this study it could be argued that the frequent mention of under-staffing reported in the researchers' fieldnotes reflects a prejudice of HCAs which might not be corroborated by managers. While not denying the possibility of such bias, the team approach to data analysis taken here does offer some protection, assuming that not all researchers are equally prone to 'going native'. Given that the focus of the study is to understand HCAs, the impact of empathising fully with the subjects is not likely to be detrimental to the findings, but readers may choose to interpret these in the light of that possibility.

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3 Context and duties of the HCA role

The aim of this section is to provide the reader with a good understanding of the functional role of the HCA on an inpatient dementia care ward. In this, it highlights both the concrete duties and skill-sets required of HCAs and the social relations which evolve from working full-time on the wards. The subjective meaning of the HCAs' social ties, stresses and motivations associated with the job role are then discussed in Section 4. In subsequent sections we 'zoom out' from the functions and roles of HCAs, each successive section adopting a more abstract level of analysis. First, we look at the interaction between HCAs and the care environment, arguing that they have a distinctive and largely unacknowledged impact (Section 5). Then we explore the policy underpinning dementia care and workforce development relevant to this group, with reference to person-centred care (Section 6). In Section 7, we bring together data pertaining to stress and coping in the light of the Health and Safety Executive's stress management approach, and Section 8 investigates the recognition and involvement of HCAs in the clinical arena. Finally, in Section 9, we summarise our findings and briefly discuss their significance.

3.1 The settings

As noted earlier, the wards in the study were located in three hospitals across one large NHS Trust. Each site provided inpatient care for older people with dementia and other mental health problems and was structured according to the same occupational hierarchy. Nurses and HCAs had the same contractual conditions and staff were organised according to similar shift rotas. Though the layout and furnishings varied, each ward contained the same basic elements: bedrooms, bathrooms/toilets, dayrooms, a nurses' station or offices, and clinic rooms. Figure 1 below illustrates the distribution of staff ages, showing a younger staff group in Ward C, and Table 3 provides details of the workforce size and composition on each ward.

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Figure 1. Staff age-group distribution

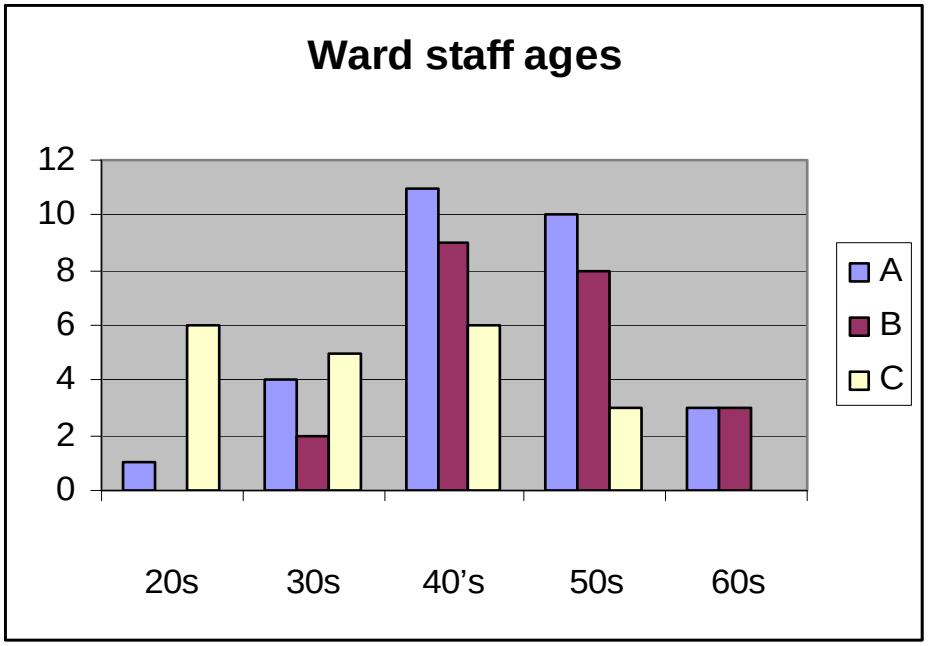

Table 3. Ward statistics

	Ward A	**Ward B**	**Ward C**
Beds (M/F)	25 (10/15)	13 (M or F)	13 (M or F)
Staff Total	30	26	23
Non-white staff	5	3	5
Staff turnover in 2008 Average for HCAs in Trust 7.7%	3.4% 2.8%		9.7%
Band 5/6/7 QNs	14	9	10
Activities/Environment Co-ordinator	1 2		1
Band 2 HCAs	15	15	12
QNs by gender	F:11; M:3	F:8; M:1	F:9; M:1
HCAs by gender	F:12; M:3	F:15; M:0	F:12; M:0

On each ward, the day was largely dictated by a routine set of tasks. However, within this routine there was a degree of variation, with Ward A

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being the most routinised. The day was roughly broken up into early shifts (07:00 to 14:30), late shifts (13:30 to 21:00/30) and night shifts (21:00/30 to 07:00), with an overlap for 'handover' from one shift to the next. Early shifts were heavily structured by routine demands – waking, assistance with activities of daily living (ADLs), breakfast, and lunch – while the only routine tasks on late shifts were tea and dinner; the main tasks on night shifts were to put patients to bed and perform periodic checks through the night. Additional routine tasks which were performed throughout the day included 'toileting' (as required), medication (two to three times daily), baths (one to two weekly per patient) and physical observations as required. To a varying extent across the wards, HCAs, along with nurses, had responsibilities for patient care plans, feeding and bowel charts, and incident reports.

3.2 Job terms and conditions

Under the Agenda for Change job profile, HCAs such as those observed in this study are referred to as 'Clinical Support Worker Nursing (Hospital) Band 2' (salary range £13,233 to £16,333 in 2008-09). The formal job statement requires that this staff group: 'Undertakes personal care duties for patients in hospital or similar settings and reports patient condition to qualified staff'. HCAs are also known as health care support workers, personal/clinical support workers, nursing assistants, or auxiliary nurses. The term consistently used in the wards studied here, however, was 'HCA'.

The HCAs' role purpose as stated in the wards' job description is: '[t]o assist qualified nurses in carrying out their duties with regard to the physical, psychological and spiritual care of the individual patient with particular emphasis on a patient-centred approach'. The context of the work is described as: 'an inpatient Ward for older people with a range of mental health problems, providing acute mental health care to informal patients or patients who are detained under the Mental Health Act'.

In terms of physical, emotional, and mental effort, the job description states that HCAs are expected to work under the following conditions:

- Moderate physical effort for several long periods during a shift, including manual handling of patients and equipment.
- Work patterns that are generally predictable; may occasionally be required to participate in unpredictable events dependent upon the fluctuating needs of the patient group.
- Frequent concentration.
- Incidents of verbal and physical aggression.
- Constant noise from patients and the environment.
- Frequent exposure to highly unpleasant working conditions.

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- Regular exposure to distressing or emotional circumstances, such as physical illness and complex/ challenging behaviours due to the nature of the mental health problems.

Full-time HCAs work five early or late shifts per week with some occasional 'long days' (07:00 to 21:00/30) which count for two early or late shifts. Full-time night staff are allocated three or four shifts per week, amounting to full-time hours at the end of the month. The working week for most HCAs consists of a mixture of early and late shifts, about which they were notified through a monthly rota, four weeks in advance. We observed that requests for annual leave and days off were usually granted if made in good time or accommodated by swapping duties with other members of staff.

HCAs are accountable to the modern matron/section manager through the ward manager. In terms of paid carers on the ward, they are at the bottom of the hierarchy but still retain the major responsibility for hands-on patient care.

3.2.1 A day in the life of an HCA

Following arrival on the ward, the daily routine usually began with making a hot or cold drink and putting coats and bags away before handover. Once handover had been called, HCAs joined the other staff in a ward meeting room or office, where a nurse from the previous shift provided an update on each patient. On early shifts, handover was followed by a group chat during which staff caught up with one another before setting off to wake patients and assist with their personal care. On late shifts, HCAs went directly to the dayroom to relieve morning staff.

Early shifts were busier than 'lates' because HCAs had a ward of patients to get up, washed and dressed as well as two meals (breakfast and lunch) to prepare, serve and tidy away. HCAs spent the relatively short time between meals taking a break for breakfast (with patients in the dayroom or in a separate room, depending on the ward); talking with or assisting patients; chatting with other staff; and preparing the kitchen, dayroom and patients for lunch.

Late shifts were relatively less structured, with families visiting patients and few set tasks to complete until teatime. HCAs often started the late shift quite slowly: sitting among patients and other staff; occasionally making patients an afternoon drink; or (rarely) working in the office on E-learning. By contrast, the dementia wards often became quite noisy and unsettled as the evening drew in (see 'sundowning' in the Glossary). The latter half of late shifts involved tidying up after dinner, taking a meal break and, on wards B and C, helping several patients change for bed in order to reduce the workload of the night staff.

Throughout all shifts, HCAs conversed with one another, with patients, and other staff on the ward (including nurses, activities co-ordinators and care environment coordinators). Doctors were present for 'ward rounds' on one to two afternoons per week, during which they met with nurses, patients

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and families. HCAs had minimal interaction with doctors, who were more likely to approach nurses during admissions and ward rounds. HCAs were rarely, if ever, present for ward rounds and instead spent this time monitoring patients.

Although appearing more relaxed, the late shift was said by many to 'drag' more than early shifts and the restless atmosphere after five o'clock often led to a stressful end to a long shift. However, too many early shifts can be physically taxing; therefore HCAs and other nursing staff tended to favour a mixture of early and late shifts across the working week.

3.3 Skills and capabilities

Job descriptions can sometimes be over-inclusive, embracing activities that are seldom undertaken, whereas by contrast people may regularly complete tasks which are not part of their job description. Therefore it is important to describe here what we *actually* observed HCAs to do. In the following sub-sections, we present our findings about how HCAs worked in relation to their duties and structural factors, using illustrations from the researchers' fieldnotes. Overall, we found that the HCAs possessed a range of skills and expertise which enabled them to cope with almost any situation on the ward, from managing challenging behaviour to end-of-life care. Multitasking and resourcefulness were additional capabilities we observed.

3.4 Assisting with activities of daily living (ADLs)

The job description states that HCAs are to 'assist patients, according to the plan of care, to carry out their activities of daily living'. We frequently observed HCAs to use their skills to assist patients in washing, dressing and using the toilet and such duties were completed with skill and confidence. There were many fieldnotes describing this process, while the HCAs' sense of competence in this regard was demonstrated in several instances where they judged other staff to be less capable than themselves. This general sense of professional expertise extended in many cases to making judgements about risks surrounding patients' mobility and assessing their moods and abilities.

3.5 Support and oversight

According to the job description, HCAs are to 'prioritise own delegated workload with support from a qualified nurse'. We found that in practice they had scope to work with considerable autonomy on their routine care tasks. The approach taken to these tasks therefore varied across the wards. Individual HCAs' recognised the differences in approach between members of the team, tending to refer to their own personal approach as superior:

As we bathed several of the male patients one after another, H/SN showed me her various techniques, pointing out specifically that 'this is the way I do it'. (Fieldnote, Ward A)

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H/HA takes pride in her methods of work over others, be it in dressing patients, handling, feeding patients or just putting food in the oven. (Fieldnote, Ward C)

I washed him and H/AI shaved him – she says she really enjoys shaving the patients and doesn't mind wet shaving as long as the razors are decent, but prefers the electric ones. She said that she puts a bit of talc on before she uses the electric ones which apparently makes things smoother and more comfortable. (Fieldnote, Ward B)

Generally, HCAs and nurses worked well together within the team. Occasionally, an HCA would criticise a nurse who was perceived to have less experience or insight than the HCA. For the most part, however, HCAs' routines and duties were so well-practised that they only required nurse supervision in exceptional circumstances.

3.6 Managing patient wellbeing

HCAs are required to 'assist in providing the optimum comfort for the individual patient consistent with their agreed care plan'. We found that HCAs continuously ensured that patients were as comfortable as possible, some going out of their way to achieve this. One worker was even known to have sewed and adapted patients' clothing to maximise their comfort (and staff convenience, because this prevented frequent changes of clothing). Efforts were made to overcome language barriers between staff and non-English speaking patients and, when patients were distressed, HCAs often comforted them with actions as well as words:

The male patient who becomes very distressed and cries was comforted greatly by H/CO who warmly cuddled up next to him, whilst on his observation, putting her arm around him and letting him snuggle into her, putting his head on her chest. (Fieldnote, Ward C)

3.7 Patient supervision

HCAs were expected by their job description to 'escort patients to other departments within the hospital' and to 'participate in both intermittent and constant observations in line with local and Trust policies and procedures'. Intermittent and constant observations were used almost exclusively on Ward C; this was a key issue for staff, who suffered increased staffing pressures as more patient observations were allocated. On Wards A and B, such observations were not noted.

3.8 Information management

According to their job description, HCAs must 'report incidents, near misses and hazards to the nurse-in-charge', 'work under the supervision of a qualified nurse, reporting back concerns or queries at all times', 'receive from and give reports to other nursing staff on the individual patients' condition and progress' and 'document daily progress in the patient's running records'. We found that communication between HCAs and nurses

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in terms of patient information, incidents and progress was well-supported and maintained on all wards. Nurses who had been off the ward often asked HCAs to fill them in on a patient's presentation or physical wellbeing. Likewise, HCAs were comfortable approaching nurses to ask advice, report incidents, or query abnormalities noticed in individual patients, but such exchanges took place during the shift rather than in handovers. We noted that the recording of such information differed across the three wards. On Ward A, the updating of patient documents and notes remained within the office walls and in the hands of qualified nurses. On Ward B, patient notes were mostly the responsibility of the qualified nurses; however, nurses occasionally brought files into the dayroom and invited HCAs' contributions. On Ward C, HCAs played a large part in writing everyday patient information such as behaviour, eating patterns and assistance with ADLs. Here, notes were completed by HCAs together in the shared space of dayroom, then signed off by the nurse in charge.

To the extent that they exchanged information with nurses and utilised patient records, it may be said that HCAs were 'working as a member of the multidisciplinary team maintaining effective communication and good relationships'. However, they were never observed to participate in ward rounds, which were the only routine opportunities for the whole team to meet together.

3.9 Laundry and cleaning

The three wards differed somewhat in terms of ensuring 'safe custody of patients' clothing and property'. On Ward B, property was entirely the responsibility of the HCAs, who would sort, fold, and put away patients' clothing on return from the laundry. On the other wards, HCAs had minimal responsibility for patients' clothing, which was instead the responsibility of patients' relatives. However, HCAs on Wards A and C *were* expected to wash heavily soiled items or clothes that the patient required immediately, such as slippers, shoes and underwear. In cases where a patient had no relatives visiting, Ward A provided hospital pyjamas which were purple in colour so as not to look too clinical, while Wards B and C kept stocks of former patients' clothing, which were washed by the hospital and sorted by HCAs. On all wards, relatives were responsible for labelling clothes and other property in order to ensure safe custody.

HCAs were occasionally instructed by nurses or care environment coordinators to clean areas of the wards and equipment; however, this was not observed across all three sites. HCAs did clean the dayroom chairs and tables with disinfectant as part of the night-shift routine on all three wards.

3.10 Seldom-observed roles

An aspect of the HCA job description which was difficult to pinpoint was 'maintaining a stimulating environment by participating in social interactions and therapeutic activities with patients and their carers'. This was seldom acknowledged by the HCAs to be part of their role. Some claimed to have withdrawn from engaging in patient activities since a designated activities

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coordinator had been hired. However, we often observed HCAs conversing with patients and taking steps to increase their level of awareness or decrease their anxiety. Without explicit acknowledgment, that is, the HCAs often provided stimulating or therapeutic activity through what they saw as routine care.

Although the family and friends of patients have a significant presence in daily life of the ward, we found little evidence of consistent interaction between them and the HCAs. On Wards A and C, visitors came in the afternoons, especially on ward round days, while visiting hours on Ward B were more relaxed. When visiting hours coincided with routine downtimes on shift, they sometimes allowed staff to take informal breaks and catch up with one another; however, we also observed staff sitting among visitors and patients during these times. Our observations and interviews revealed that there was a complex dynamic operating between relatives and HCAs who, to some extent, had supplanted them in providing care for the person with dementia. This is explored further in Section 5.5: *Interacting with families*.

3.11 Clinical care

A final condition of the HCA role is to 'carry out duties that may be required after training'. We found that the scope of HCA activities varied between wards. On Ward A, the largest ward, HCAs were involved in most aspects of medical care to some extent, including dressing wounds, taking blood pressures and blood sugar monitoring. In contrast, on Wards B and C these tasks were felt to be exclusive to the role of the qualified nurses: while HCAs on these wards expressed confidence in their expertise in basic patient care tasks, this confidence did not extend to more clinical tasks.

On every shift on Ward C, both the staff nurse in charge and one HCA kept a set of keys which included a 'ligature key' for access to a knife drawer, should any patient be found with a ligature:

H/HA said that she feels that HCAs should be paid more for having to carry [the ligature keys] and have such a responsibility. There are many things the HCAs do that they feel warrants better pay but they have never been given this, yet they carry on. (Fieldnote, Ward C)

3.12 Conclusion

In Section 3, we have considered the formal dimensions of the HCA role, both in principle and in practice, and the variations which we found across the study sites. The range and scope of activities is summarised in Figure 2 below, and readers may also wish to refer to the Glossary (Appendix 1) for the terms and acronyms used. We present this evidence to pave the way for a more in-depth look at the impact of the HCAs on the patients and the ward environment in the following sections, where we assert that their distinctive contribution goes well beyond the terms of the formal job description. Over and above the discrete competencies discussed here, we argue that HCAs orchestrated the emotional climate on dementia wards

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and, without such interventions, the care of individual patients could not be satisfactorily accomplished.

Table 4. HCA tasks

Assistance with ADLs including: washing, bathing, dressing, toileting, feeding
Assistance in medication administration
Basic life support
Bed making
Clothing
Cleaning
Continence care
End-of-life care
Equipment knowledge and use
Food hygiene
Kitchen duties: preparing and serving food, washing dishes, tidying up
Ligature key procedure
Managing violence and aggression
Stock control
Taking urine/ faeces samples
Using medical devices and equipment: catheters, colostomy bags, blood pressure machines, BM readers, chair scales, rotundas, hoists, beds, baths, wheelchairs
Updating patient care plans, notes, feeding, and bowel charts
Wound dressing

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4 Supports and 'drivers' of the HCA role

HCAs have a low occupational status, are poorly paid and have limited opportunities for career development. The majority of patients on these wards were in quite advanced stages of cognitive degeneration, and many were physically frail and dependent. Many patients displayed behaviours and emotions that presented a considerable physical and emotional challenge to ward staff. The environment as a whole could be characterised as distressing and unpredictable. Yet staff turnover is around 7.5 percent on average and much lower in some places. This compares favourably to nursing homes, which are among the most similar environments to the settings studied (19, 20).

The research questions leading this investigation were grounded in our attempt to understand this paradox. This section will describe some of the things which challenge and motivate HCAs, the 'strain and satisfaction' of this work (21), in order to take our understanding of what it is like to be an HCA beyond the objectively observable features described in the foregoing section. We have described *what* HCAs do; now we aim to give an account of *how* they do it, with regard to their social, emotional and psychological functioning. This is tied up with their motivation and the rewards they derive from the role; in other words, *why* they do what they do. Before addressing these individual issues, we describe the teamwork context within which HCAs operate. Thus, the present section seeks to understand some of the subjective experience of being an HCA by looking first at the working group or team, and secondly at the individual members. In between, we briefly consider the function of humour in relation to the work undertaken by HCAs. From this deeper understanding of group and individual dynamics, we explore the HCAs' perspective on the work itself and the impact it has on them personally.

4.1 Staff relations and 'the team'

The closeness and longevity of staff relationships and the manner in which staff were able to work together efficiently and sociably as part of the front line emerged as a major theme from our analyses. Team working makes up part of the official job description for HCAs and is cited often in policy guidelines for improvements within the dementia care workforce (2, 22). Baker *et al* (23) conclude from their review of evidence concerning medical team working that:

A team's utility and efficiency is tied directly to its team members and their ability to integrate various personal and situational characteristics. Each team member must understand the technical and tactical considerations of the assigned task, as well as the strengths and weaknesses of their teammates. In addition to carrying out their own responsibilities and altering them when necessary, each member must also monitor their teammates' activities and diffuse potential team conflicts. Effective teams

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exhibit these competencies while maintaining a positive emotional attitude toward the team itself.

The practical functions of a closely integrated team are evident: it contributes to the effectiveness of a multidisciplinary approach, optimising the use of complementary skills, and it structures relations between HCAs, staff nurses and management, providing a platform for delegation and supervision. Our findings indicate that each of these practical functions is associated with emotional benefits, contributing to the wellbeing of team members and to a collective identity. Practical and emotional benefits explain the symbolic importance of 'the team', from which staff draw pride and protection, job satisfaction and a sense of wellbeing. These functions will now be described in more detail.

The three wards each hosted a tightly-knit social community of HCAs characterised by close, deep and enduring relationships. The extent to which staff drew on these relationships to work efficiently and sociably on the front lines of care emerged as a major theme from our analyses. As well as contributing to a sense of safety, pride, and collective identity, the team provided the type of consistent emotional attachment that by definition cannot be established with acutely dementing patients. We infer that the relationships formed between staff, based on trust and interdependence, supplied an important coping mechanism. This echoed findings from the literature that collegial support is especially important among those caring for people who can offer little acknowledgement or appreciation (24).

The bonding effect of close staff relations was expressed through the staff members' self-disclosure. The sharing of personal information was a regular feature of any shift, not only on formal or informal breaks but also, often, during work-related tasks. Topics of personal conversations ranged from home decorating, family issues and health and illness, to more intimate information, covering physical, emotional or sexual matters which are more commonly shared between close friends and family.

For some staff, this intimacy continued off shift, at Christmas parties, on summer boat trips and during other informal social gatherings. These outings signified the genuineness of staff relations and provided a source of stories and teasing that extended far beyond the events themselves. Sincere and lasting relationships that can be maintained outside the workplace – as well as providing support within it – were acknowledged to be a source of wellbeing. In response to an outsiders' advice to stop working, one HCA stated '*I can't – it's my social life as well!'* (H/T1, Ward C), which implies a sense of social fulfilment which may not normally be associated with the workplace.

4.1.1 Team working

The bonds between staff enabled them to protect one another from stress and strain, both actual and anticipated:

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H/PN said they worked together to watch out for and protect each other. 'She'll say, "I'll go and get so-and-so up", and one of us will step in to say "no, you're all right, I'll do them" – you know, to protect her, so that she doesn't have to work with that patient again'. (Fieldnote, Ward A)

H/FA told her that she was fine and that she was a good nurse. (H/FA is in her second year of training). 'Yeah!' Q/WD said punching her fist half way in the air. H/FA told her that when she herself had qualified in a year and felt she was a bad nurse she expected Q/WD on the phone and ready with the pep talk that she was doing fine. Q/WD laughed and said she'd "be ready". (Fieldnote, Ward C)

Sensitivity to each others' needs, and the trust that it promoted among staff, was central to the formation of the team identity. In turn, the group shared a work ethic from which HCAs appeared to draw much pride, and 'the team' took on a symbolic significance for those who felt its positive effects. Team members made frequent reference to the importance of 'the team' and 'teamwork' for the fulfilment of a variety of functions in their role. Just as one HCA stated in a break-time discussion concerning the mix of staff on shift '*it's about being a team, isn't it?*' (H/LA, Ward C), HCAs constructed and maintained a strong self-characterisation of 'good team', which they sometimes compared unfavourably with teams on other wards, whom they regarded as more task-oriented or routine-dominated. Implicit in this positioning was the notion that a 'good team' is required in the interests of more personalised approaches to patient care (25, 26).

The value placed on the team ideology was also revealed through the criticism (or appreciation) of fellow workers who were either detrimental (or beneficial) to the construct of the team, effecting a kind of social control over the staff group. Those who failed to promote the values of the team risked distancing themselves from staff and enduring strained relationships:

This reminds me of when Q/WD expressed her annoyance, on our nights, with the dayshift staff who allow [patient name] to sleep all day long, even when she asked them not to in handover, which meant she was awake all night. The day staff had let her sleep all she wanted in the day as it made their shift easier and less stressful. (Fieldnote, Ward C)

While on break, we talked a bit about H/CY. H/SN called her selfish, saying 'it's someone like her who gives the rest of us a bad name' and arguing that 'we're a good team, really – and to be honest,' lowering her voice a little, 'I think we'll be a better one when she's gone'. I asked whether most people felt that way – and she replied that she thought so but that 'there's a lot of two-facedness round here, you know'. (Fieldnote, Ward A)

The first fieldnote suggests that the team is defined by the group of staff on a given shift; staff 'on nights' position themselves as a team relative to the daytime staff. In the second fieldnote, the team is broader, differentiated from an individual scapegoat who re-affirms the norms and values of the team through transgressions. Created and reinforced through such judgements, team norms establish what one researcher referred to in fieldnotes as an 'inclusive' ethic: a set of behavioural norms which can be

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powerful determinants of behaviour, with both positive and negative effects on the care process. Team norms extend to breaks as well:

The dominant 'inclusive' ethic has the potential to create the outsider. … I felt this the very first time H/AI said to me that I could eat where I wanted, but 'most of us' eat in the dayroom. (Fieldnote, Ward B)

Despite the potential for the team ethic to marginalise and even expel nonconformists, it appears that, once a collective ideology has been created, it is a vital source of support and pride. This observation was supported extensively in staff interviews, in which the team ideology and its protective and rewarding effects were widely acknowledged:

Oh brilliant, they really are good, you can trust them, you know if you need them they'll be there, there's no hesitation. With all the staff here we're a team. (H/NE, Ward B)

Yes, and we all get on, there's nobody that don't get on sort of thing, we all do get on quite well. Which I think you need to, which is part of the team building isn't it? (H/T1, Ward C)

Across the three research settings, a pattern of responses to questions about 'the team' emerged, beginning with an affirmation of the 'good team', followed by an acknowledgement of certain flaws in practice, *but* with the conclusion that these flaws can be seen as inevitable and overlooked in the interests of motivating the team. Thus the team remained an effective motivator despite its occasional inconsistencies:

I think we've got a good team, I think we work really well. As I say, we all have our off days and we all think 'oh God, ask someone else to do it', but – you do, you all have – but I think as generally we've got a good team, I think we do really work well. (H/HN, Ward A)

And I think we have got a good team, and if there is anything to be addressed we can address it to more or less each other, we can tell each other and we argue, we fall out, we're bitches, but that is as far as it goes, you just pass it over and you just get on with your job. (H/SN, Ward A)

4.1.2 Group identity

Team identity may be considered within the theoretical framework of 'dirty work', which was proposed by Hughes (27) to describe those occupations that are likely to be negatively perceived and therefore stigmatised because of their physical, emotional or moral 'taint'. As Ashforth and Kreiner (28) explain: 'The stigma may be communicated directly through putdowns, reduced deference and respect, and demeaning questions ("How can you do it?") and more subtly through discrimination and avoidance'. Despite this stigma, research suggests that people performing dirty work tend to retain relatively high occupational esteem and pride in a number of ways: by carefully constructing an 'occupational ideology' which recasts their work in terms of its higher and honourable purpose; emphasising their superior skills in carrying out the role; and policing the boundaries between their own group and others (28-30).

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We gathered substantial evidence which suggests that the HCA role is indeed devalued by others as dirty, unskilled, and thankless. At the same time, the HCAs articulated considerable pride in the work that they do. They appeared to sustain this pride in the face of considerable stigma, and without the compensation of a high salary or other job benefits. We found that they made a considerable investment in a positive collective identity. This largely involved constructing their identity as care 'experts', in implied or overt contrast to other groups with which they have daily contact.

First, the HCAs generally enjoyed a positive, close relationship with qualified nurses, which was clearly reinforced by 'mucking in together' in the daily tasks of patient care. This helped maintain a shared identity among HCAs and nurses in comparison to other groups. However, nurses by definition devote more time to clinical nursing tasks (medications, dressings) and in the office (completing paperwork and communicating with those outside the ward) while HCAs spend all of their time 'on the shop floor'. We observed that HCAs interpreted this institutionally-codified distinction between the two groups in a way that privileged rather than devalued their own knowledge and skills. According to their interpretation, qualified nurses may be 'superior' in terms of their formal qualifications and skills but HCAs have a different form of 'superiority', due to their greater direct engagement with patients. HCAs enacted this distinction by seizing opportunities to 'trump' nurses' knowledge and skills in specific situations:

H/BA was quite confident in telling QM/AG that we weren't going to dress the patient now and the reasons why. When QM/AG had left the room, H/BA turned to me and rolled her eyes… (Fieldnote, Ward C)

In contrast to the subtlety of the line that HCAs drew between themselves and nurses, the line between HCAs and consultants was much clearer. This may derive from the professional distance between the two groups: relative to consultants, HCAs felt particularly devalued and disregarded, therefore they retaliated through explicit criticism. In one fieldnote from Ward C, for example, H/HA referred derisively to the 'white coat fallacy', which is that 'doctors know all': '*"But they don't!" she said heatedly'.* Such critiques threw into relief the salient aspects of the HCAs' own role; for example, by referring to the doctors' ineptitude with 'challenging' patients, HCAs implicitly highlighted their own experience, competence, and communication skills. This polarisation of staff groups, which occasionally amounted to hostility, is clearly likely to have a detrimental impact on the effectiveness of the multidisciplinary team, with knock-on effects for patient care.

We noted that HCAs regularly alluded negatively to 'care-home staff' as a reference group, albeit with sympathy for the relatively unfavourable conditions in which the others must work. Through these unfavourable comparisons, HCAs appeared to assert that a superior level of care was provided on their own wards. On Ward C, for example, H/LA compared her experience of care-home routines to a conveyer belt of patients lining up to be washed, toileted, and so on.

We also found that, in each research setting, the HCA team further reinforced their sense of group worth through comparison with other

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hospital departments and wards, which were described as 'incompetent' or 'unable to cope' when it came to caring for patients with dementia. For example:

I learned in handover that the patient's operation had been conducted successfully and that she is due back in the ward within a day or so: 'They'll send her back here as quick as they can', said Q/MB, 'can you imagine them coping with her up there? Shouting all night long?' And QM/DZ told the story of how the medical ward had called down for meds in a panic, though they'd been briefed in advance of how agitated she might become. (Fieldnote, Ward A)

Finally, our observations suggest that HCAs positioned themselves in stark contrast to the rest of the world. We often heard from staff that nobody on the other side of the locked ward doors could understand the reality of caring for persons with such acute cognitive and physical impairment on a daily basis and nor, probably, could they 'cope' if they tried. As the researcher from Ward A recorded on one shift:

[They talked about how] 'nobody gets it': <u>nobody</u> from outside Ward A understands what it's like to work here. (Fieldnote, Ward A)

This indicates a strong identity or even 'subculture' among the HCAs. Our data confirm that the HCAs work under all the conditions which have been identified in previous research as important for the formation of subcultures, including: the use of collective socialisation, high task interdependency, physical proximity between individuals, clear physical boundaries and isolation, and group longevity (28).

4.2 The uses of humour

Humour was found to be a mechanism which consistently reinforced positive staff relations. We observed a level of almost constant good humour among staff, with participation in jokes, pranks and affectionate teasing a group norm. Humour served to bond staff closely, often through its cathartic effects. In terms of teamwork, humour seemed to provide light relief for the group, thereby facilitating periods of recuperative 'downtime' while on shift:

When Q/EK entered the office for handover, H/BA and I watched her through the window take off her scarf and gloves, throwing them around the room, following by her coat as the others sang the strip tease song. We both laughed as did everyone in the office. (Fieldnote, Ward C)

Sometimes, humour served to highlight and reinforce norms of care, without the problematic fallout which a confrontation or critical stance might generate:

Q/CR and H/SN were absent for a while because they went to give [patient name] a bath – leaving amidst jokes from the other staff about how they'd be gone for two hours, talking and presumably wasting time. (Fieldnote, Ward A)

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Humour and close staff relations are interrelated, in the sense that closeness is required to use humour, and using humour re-affirms that closeness. A good example of this is the manner in which staff used humour to express their sensitivity toward each other:

H/GL asked me whether I was enjoying it now as he hadn't seen me for a while. I told him that I was really enjoying it but there was still times when I felt as though I didn't know what I was doing. H/GL laughed and said that this was OK as he had been doing this for 19 years and still didn't know what he was doing. He went on to say that H/T1 (who was walking nearby) had been doing it for '50 years and still doesn't know what she's doing!' (Fieldnote, Ward C)

Humour was not reserved just for staff; patients sometimes participated in the repartee, as did visitors. In the following excerpt, mimicry was used as a form of humour, which (leaving aside the fact that a patient is the unsuspecting target) affirmed the participants' membership of an in-group, while providing reassurance on the job:

Having heard the effects of my struggle to adjust the water temperature, Q/WT and Q/CR asked me if I was doing okay, then did light-hearted imitations of [patient name] saying (in her characteristically loud and nasal sing-song tone) 'it's coo-o-o-old!' I said I was fine but couldn't get the hang of the taps – and was (gratefully) reassured by Q/CR's reply that 'that was me with [patient name] yesterday – it's impossible to get the temperature right'. (Fieldnote, Ward A)

The uses and functions of humour in these settings warrant more attention that can be given here. Further research would be required to draw parallels with the uses of humour in other settings.

4.3 Motivation and intrinsic rewards

In the interviews, when we asked HCAs directly about their motivation to do this work, we learned that, at a general level, the caring philosophy which is central to nurses' understanding of their work (31, 32), is also centrally important for HCAs. In other words, HCAs appear to be motivated by the opportunity to care for those in need. In the context of these particular wards, this is perceived as an important contribution to society, as many of these patients have few alternative care providers. As put very simply by H/HN on Ward A: *'what you do is worth doing'.* This contribution was voiced by some HCAs as a sense of 'purpose':

I think it's a very demanding job, it's a very stressful job, but you're also taking away at the end of the day that you're there for the purpose of helping people and giving a part of yourself to people. (H/BN, Ward A)

I enjoy it – caring for others who are less fortunate than me. (H/GL, Ward C)

We found that often this sense of purpose had been initiated by personal experience with a family member who had Alzheimer's disease or another mental health problem, or in the face of personal loss:

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My dad had Alzheimer's … I wasn't actually doing the job then and the manager who was on here before kept asking me if I wanted a job. (H/SN, Ward A)

My dad passed away when I was young and I kind of felt like I couldn't do anything about it … so doing this kind of makes me feel a bit like, you know, I can do something about it and make a difference. (H/PN, Ward A)

Really it was inspired by family background, mother had a mental issue… I realised I could do more than just be an ordinary person. (QM/NN, Ward B)

The impact that this kind of personal experience can have on the quality of care is acknowledged here by one of the staff nurses:

A lot of the nursing assistants that work here have relatives that have either had some form of dementia or strokes, and you see the difference it makes. (QM/SR, Ward A)

And, here, observed by one of the researchers:

For H/SN, this personal experience allows her to empathise with patients and their families – and has also taught her the importance of being able to laugh about things along the way. (Fieldnote, Ward A)

The implicit rewards of caring work also emerged as a key theme in many interviewees' accounts of their work motivation. In the following excerpt, the potential mutual benefit of this relation is expressed:

The patient care … That is really the time where you're actually contributing the most and also gaining the most from that. (H/BN, Ward A)

The prognosis for dementia is very poor; patients are not expected to 'get better' in the sense of making a recovery. In spite of this, many staff are able to draw positively on the differences which they observe on a day-to-day basis, which they see as 'improvements'. This may be particularly so on Ward A, where there is more variation in the presentation of illness and, therefore, the patients' prognoses.

I enjoy it when a patient comes in really poorly and then they get … you can see them getting well. (H/BC, Ward A)

Small signs of progress were a source of satisfaction across all settings:

You can see the difference in the day-to-day, you can, and you know you are doing a good job. (H/NE, Ward B)

However, for some HCAs, the poor outlook for most of the patients did limit the sense of reward they derive from their work:

I can't say it's rewarding because it's not, no. If they were going home, then … yes. (H/SN, Ward A)

Interestingly, this limit on reward did not inhibit the same HCA's 'love' for the job:

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You can go home and think 'I've had a good shift, I've done a good job,' but you don't actually get any satisfaction … but I just love it 100 percent, absolutely 100 percent. (H/SN, Ward A).

It seems that this HCA related the notion of 'reward' and 'satisfaction' to good patient outcomes, which are rare on these wards; yet nevertheless continued to love the work '*100 percent*'. This again illustrates how staff derive rewards from small improvements, for instance in the physical comfort or emotional wellbeing of the people in their care. In relation to this, many staff expressed satisfaction in providing assistance with ADLs:

I love to do the patient's hair, I think it looks nice and they feel nice as well. (H/SN, Ward A)

I get a lot of satisfaction getting them up in the morning, doing their hair, making sure they had a good breakfast. (H/IN, Ward B)

As described in Section 3, only a minority of HCAs undertook clinical care, but those who did described it as a source of satisfaction:

I love doing dressings, absolutely love it, don't know why, I just love dressings. (H/SN, Ward A)

I do like the medical side, the wound dressings and, I don't know why, everyone thinks I'm weird for it, but I like doing the pressure sores (H/PN, Ward A)

Another source of satisfaction is the personal pride that staff were often able to draw from successfully completing a physically or emotionally challenging task or navigating an unpredictable situation:

Some days it could just be a patient, you know, who is really aggressive… You do something for them and they just go 'thank you', and it's like 'What?' (H/PN, Ward A)

What you see today is not what you see tomorrow … enticing your brain to think, 'what could be wrong with them?'… Trying to think, 'how else can I help them?' (Q/ZR, Ward B)

Getting a response from a patient, you know, we've got one here now, the one I said just stares, she always remembers my name. (H/GL, Ward C)

Satisfied to some extent with these small achievements in daily care and communication, HCAs tended to perceive as precious those moments in which they glimpsed features of a patient's personality or past life:

Sometimes it's a delight to talk to them, and see their aspects of life that they've led, you know, they've lived, they're a life of knowledge. (H/BN, Ward A)

You get to know them, and I like talking, 'what did you used to do?', 'what are your hobbies?', 'do you have any pets?', 'did you like to go dancing?' and things like that – and the things they come out with, it's amazing. (H/BC, Ward A)

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4.4 Engagement in caring

The reward that staff gained from caring was frequently evident in the manner in which they went about their work and interacted with patients. Our observations revealed that care could be expressed in a number of different ways: in the affectionate approach staff often took with patients; in the frequency with which their communication with patients was expressed in physical contact; in their recognition of the personhood of the patient expressed through their respect for patients' dignity and empathetic responses to distressing circumstances; in the humorous relations that were often expressed between staff and patients; and in their knowledge of patient histories and habits and ongoing attentiveness to patients' needs. These points will be expanded on here in relation to the notion of 'engagement' in care work, under which affection, attentiveness, humour and empathy can all be grouped.

One of the most immediately obvious ways in which staff expressed care was through both verbal and physical affection toward patients:

A/RE then sat down and carried on talking with H/HA at the table, whilst Q/SM went to finish giving patients their medications. After giving [patient name] his medication, Q/SM thanked him. He grinned at her and she smiled back at him telling him he was lovely. 'Love you' he said to her. She walked away saying to me: 'Yeah, really aggressive, isn't he?' rolling her eyes. (Fieldnote, Ward C)

As she walked away she spotted [patient name], sat opposite me at the table reading papers. 'Hello [patient name]!' she said, grinning and putting her arm around her to hug her and asking how she was. [Patient name] told her she was alright and H/ FO gave her a kiss on the side of the forehead and told her she'd be back. [Patient name] looked over at me and smiled, raising her eyebrows (Fieldnote, Ward C)

These excerpts make particularly clear the impact that such affection can have in terms of the relatively unusual levels of reciprocity that it may garner from patients. In the first excerpt above, such reciprocity appeared to challenge the patient's 'aggressive' reputation. This is a matter over which there was often ambivalence, however:

Many staff have a rhetoric of the unpredictability of the patients. 'You can't turn your back on any of them' is something I've heard from several people. However, in the daily work I find the assumption is much less guarded than this implies – I have observed this in myself and most others I have worked with. (Fieldnote, Ward B)

A possible explanation for the mixed messages about violence is the volatility of many patients due to their illness. Therefore, while affection is an important expression of the rewards of caring, the risks associated with physical proximity to unpredictable and potentially violent people indicate a need for discernment and caution:

You never know what is underlying … what the patient is capable of. (H/HN, Ward A)

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For longstanding staff, risk has come to be accepted as an unavoidable aspect of the work:

I mean, kicking, spitting, punching, head butting, scratching, it's constant. (H/ET, Ward B)

By contrast, as newcomers the researchers were acutely conscious of the odd nature of interpersonal relationships between staff and patients, which were distorted by the factors discussed above. For one researcher, this offset the rewards to be gained:

Interpersonal relations are often mutually oppositional and provocative and constrained by the lack of insight, communication and memory that most here experience – I find that these three things are perhaps the most persistently upsetting and frustrating things about this work and while it can be immensely satisfying to capture what seem like little breakthroughs now and then, overall these feel very momentary and can be reversed the very next time I attempt to interact with the same person. (Fieldnote, Ward B)

This sense of insecurity is compounded by the often intrusive, undignified and potentially dehumanising experience of the institutional provision of basic ADLs:

I explained to the patient that we were going to get her washed and dressed, more or less shouting it in one of her very deaf ears. It seemed she still couldn't hear me or understand me and when we tried to sit her up she 'flopped' as H/WA called it, making her very heavy to handle. H/WA told me to go round the back of her and hold her in a sitting-up position, which I did whilst trying to help undress her with my other hand. (Fieldnote, Ward C)

Thus the work of the HCA entails constantly appraising risks and maintaining rapport with individual patients, while juggling the many practical duties which they are required to perform, sometimes involving human beings who do not comprehend their meaning. Overcoming these challenges, the HCAs did find ways to meaningfully engage with patients, despite the difficulties of working in the particular institutional context studied here.

4.5 Coping strategies

Sources of stress are various, deriving not only from the risks and inherently unpleasant aspects of the work outlined above, but also from organisational factors, notably staff shortages, and colleagues' occasional failure to recognise or support each other. On the whole, however, team working seemed to operate well to protect and support HCAs on the wards against these stressors. In light of the unpredictability of the environment and the confusion and lack of insight caused by dementia, the ethos of the team led staff to be patient and calm while shrugging off the inevitable abuse:

I suppose you've got to be easygoing and I think you need a little bit of patience; well you need quite a bit of patience probably. (H/HN, Ward A)

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Yes, no matter what frame of mind you're in, whatever has gone off, whatever the situation, you've got to stay focused, yes, you can't let it take over you. (H/BC, Ward A)

Most of the time, the team could be relied upon to manage the workload and to intervene if an individual was at risk or overburdened. Within that protective organisation, individuals also utilised what we might call 'stress management' measures. Different people were observed to manage their own responses or emotions, to seek support or comfort from colleagues, and to escape, both physically and emotionally, sometimes leaving the ward, 'wandering' from the task at hand or taking a smoke break on shift.

There were also numerous accounts of stress management strategies employed off-shift, including exercise, relaxation and immersion in family-related concerns, as well as frequent jokes about taking recourse to alcohol, although we did not observe these activities. At work, however, the researchers picked up on a repertoire of psychological approaches which appeared to promote coping. When analysed, many of them seemed to serve a similar purpose, which we term here 'desensitisation'.

4.5.1 Desensitisation

By 'desensitisation', we mean a lack of response to stimuli which in another context would elicit an emotional reaction, usually an unpleasant one. Desensitisation can be seen as a form of self-protection via the conservation of emotional energies. It seems to entail a psychological distancing from the issue while in some (but not all) cases maintaining affective engagement. We observed this psychological adaptation in HCAs and some nurses, often through their use of ironic humour and conversation about things other than the matter in hand:

As I was carrying the full bedpan into the sluice room, I passed H/PN who, seeing the look of distaste on my face, said 'don't you just love your job?' I replied 'this may not be my favourite part of it, I'll tell you what'. (Fieldnote, Ward A)

Just as I was beginning to wipe away some of the faeces that were smeared all around her bottom and upper thighs – trying to keep my stomach from turning at the mess – H/AN asked me agreeably 'so, did you have a good time on Saturday [at the Christmas do]?' (Fieldnote, Ward A)

Another desensitising tactic was to reframe or underplay an experience, thus making it less threatening:

You've got to be able to take some criticism off patients because, as you may have noticed, patients can be abusive towards you and it's just like, take it on the chin and then forget about it. (H/PN, Ward A)

The protective functions of desensitisation are therefore clear: it tunes out the distressing sights, sounds and smells of the job; minimises the fear of verbal and physical attacks; provides a buffer against the emotional impact of bereavement; and enables staff to do their job efficiently, while still leaving it all behind at the end of a shift.

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A striking finding is that the HCAs were not observed to be desensitised toward their labour in any absolute or uniform way. We have shown above that they were generally capable of engaging positively with the people for whom they cared and with each other. A crucial skill for an effective HCA is to be able to achieve selective desensitisation to unpleasant stimuli, while remaining emotionally available for the rewards which can be derived from the work. This paradoxical relationship between engagement and burnout has been recognised by Vinje and Mittelmark (33). We also found that some staff were aware of the complex balancing act they were required to perform:

Yes, if you can't attach at all then you wouldn't care about the person, you wouldn't be able to do what you feel is best for them and you know, yes you've got to have some kind of attachment, but not, yes it's very … I suppose it's just that same line between … but you never know where it is, it's just, I think you just do it. (H/HN, Ward A)

4.6 Conclusion: challenges and rewards

Close staff relations, the bonding effects of humour, and a common identity in a closely integrated team all promoted a sense of wellbeing among the HCAs we observed. The ability to communicate with, engage with and form attachments to patients, accessing their life histories and developing nuanced understandings of individual habits and mannerisms, made the job rewarding and satisfying – thereby promoting high-quality, individualised patient care. Despite their low status, HCAs recognised that they perform a role which is socially important.

We identified a range of factors which appear to act against high-quality care, including low ratios of staff to patients, physical risks associated with unpredictable patients, lack of recognition, and lack of inclusion in organisational decision-making. These themes recur in the following sections in slightly different guises.

We found that the psychological strategy which we term desensitisation was widely used to enable HCAs to do their work effectively despite its inherently unpleasant aspects and the obstacles which they encountered. HCAs appeared to be selective in their desensitisation, tuning out negative stimuli while still attending to the positive rewards of the job. Within this ability to balance sensitive and personalised care against protective psychological distance is an important clue to the distinctive contribution that HCAs make to the ward environment, for which they deserve much fuller professional recognition. This contribution will make up the subject of the next section.

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5 HCAs' distinctive role and contribution

As seen in previous sections, the HCAs' formal role is to assist staff nurses in providing direct care to patients. Although this role may appear subordinate and repetitive, our findings reveal that HCAs actually exercised considerable authority and autonomy in its enactment. Throughout every shift, they made countless decisions about their workload which, we discovered, balanced the needs of each patient (for physical or medical care, verbal or tactile reassurance, entertainment or solitude, and so on) against the needs of the entire patient group, ward visitors, and other staff. Here we present evidence to support the argument that, while regarded primarily as *carers*, HCAs were also effectively *managers* of their overall environment, drawing on their practical skills, emotional intelligence and tacit knowledge of the ward to maintain relative stability, safety, and wellbeing.

5.1 Theoretical background

The autonomy exercised by HCAs in negotiating the boundaries of their role can be understood within Strauss's (34) theory of 'negotiated order' in the hospital setting. This theory suggests that, because hospitals' formal rules only prescribe roles and social relations at a general level, micro-level interactions are negotiated between individuals and groups from one moment to the next. The implication of this ongoing process is a shift in power relations such that 'lower level members of staff have more power than would appear to be the case given the formal structure of the hospital and their position in the hierarchy of authority' (35).

Thus, while the HCAs' work is formally codified in their job description, as outlined in Section 3, it appeared considerably broader in practice according to the negotiated order on the wards. Specifically, we found that HCAs exercised considerable 'practical autonomy' (30) in mediating between individual and institutional needs on the wards, and they appeared to assert some pride and mastery with regard to this aspect of their role, even though it is not explicitly recognised in their formal job description or status.

This section will explore the HCAs' distinctive contribution as 'managers of the ward environment' with reference to the three main groups between and among whom they mediated: the patients themselves, the family and friends of patients, and the staff team. We will first locate individual patient care within the broader context of the ward, examining how the HCAs deliberately balanced their attention to each patient's quality of life against the needs of other patients and ward actors. We then weigh up the benefits as well as the limitations of the HCAs' engagement with patients' families, before going on to look at the work undertaken to maintain the practical functioning as well as emotional health and self-esteem of the staff team.

The key point here is that HCAs' interactions with individual patients tell only part of the story; we understand more about the challenges, skills, and

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rewards entailed in their work when situating those individual interactions within a broader context.

5.2 Patient care in the institutional setting

HCAs rarely cared for patients in isolation: even managing individual patients in non-communal spaces such as the bedroom or toilet implied a conscious choice *not* to care for the rest of the patient group. The HCAs offset individual patients' needs against those of the overall patient group through a range of mechanisms which include organising care, managing routines, and responding with flexibility. These mechanisms will be examined in turn below.

The tact with which HCAs generally approached the challenge of individual care versus group management is brought to light through occasional exceptions. For example, the researcher on Ward A wrote about one staff member's evident bias toward the ward as a whole:

She seems a bit more traditional in her nursing style – focused on efficiency and expedience – not without compassion in her dealings with the patients, but with an apparent awareness that her job is to make the ward function smoothly as a whole, with that being kept in mind when designing individual patients' care. (Fieldnote, Ward A)

That this particular worker's approach stood out as a noteworthy exception to the general rule suggests that the functioning of the ward, though a salient concern for all, may be managed in more subtle ways by other HCAs.

5.2.1 Organising patient care

'Organising care' is the term James (11) uses to convey the skills that carers employ in providing direct day-to-day care. She suggests that, even within the hierarchy of the hospital system, nurses have some power in organising details of care, which 'may make considerable difference to the quality of life and perceptions of the people being cared for'. We argue that, like nurses, HCAs invoked their practical autonomy to 'organise care' in ways that take into account individual patient's needs *and* the institutional context.

In principle, that is, the HCAs had little influence over care plans or ward routines such as meals and bedtimes. However, over the course of each shift they made myriad care choices: deciding which patients to assist in which order, pre-empting risks of incontinence or challenging behaviour, reacting with flexibility as incidents occurred, and so on. While some of their activities were overtly directed by nursing staff, it was more common to observe HCAs exercising *de facto* control over the basic care given to each patient by deciding how it was delivered, when and by whom. In this way HCAs were able to act autonomously to negotiate some of the 'artificial barriers' (36) that can be created by a strict adherence to set routines.

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5.2.2 Knowing the patients

HCAs appeared to derive their competence in organising care at this level from their unique first-hand understanding of the patients. Our data suggest that HCAs shared a general understanding of dementia patients as deserving individuals who, due to the interrelationship between their illness and their environment, are unpredictable in mood and behaviour, and that this general understanding was enriched by their detailed and evolving knowledge of each patient's character, mood, and preferences.

An important part of the HCA role, therefore, is getting to know the patients – not only in recognition of their individual personhood but also in order to better organise their care vis-à-vis other patients. This did not make it possible to avoid disruptive incidents altogether but it did enable staff to identify and respond most appropriately to the situations that inevitably arose. As one HCA put it:

We concentrate more, as you get to know the patients, the more you know their ways, you know their habits and if they've got a bad tummy and things like that and you get to know them; the job comes easier when you get to know them. It doesn't stop you getting hit sometimes, but you're aware of, you just get to know them and understand them a bit more. (H/ET, Ward B)

5.2.3 Tactical manoeuvres

Three care tactics employed by HCAs to enhance the overall ward environment included communicating effectively, controlling the emotional atmosphere on the ward by keeping noise levels down or stimulating interaction, and managing the physical placement of patients. Each strategy gave the HCAs scope to demonstrate a range of skills, which are evidenced in our data.

Communicating effectively was key to ensuring individual patients' wellbeing while also forestalling their potentially disruptive verbal and/or physical reactions to miscommunication:

I usually go and sit and talk to a patient who is making a lot of noise or whatever but keep my voice really quiet, because usually if you talk to a patient, if you go up to their level they will go up a bit more, but if you sit and talk to a patient and you sit and talk quieter than they are, they usually come back down to your level or if you tell them not to shout they usually come down to your level – and if you do that with a few patients it usually then catches on and everyone then usually calms down. I don't know why, they just seem to follow suit. (H/PN, Ward A)

This relates to the broader strategy of controlling the general atmosphere on the ward, which benefitted patients but also improved conditions for staff. In their interviews, many staff cited noise as one of the most stressful conditions of the job:

[Noise is] no good for these patients … it does nothing for them, it's like at night-time, about eight o'clock, sometimes they walk and just go, it gets so

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loud and noisy, so what I do is switch the television off, bring it back down them to calm the system and if they want it back on it can go back on, but it needs to come down because that is how your accidents happen and you just can't afford it, so bring it back down to a calmer level and get them all settled again, because television sometimes, it drives you mad. (H/SN, Ward A)

By contrast, when the ward atmosphere was too subdued, patients became bored or disengaged and the shift passed slowly. At such times, the HCAs sometimes took it upon themselves to liven things up:

As I was getting [patient name] washed and dressed, H/RO was now getting [patient name] up in the adjacent bed area. I could hear H/RO having fun with [patient name], telling her to get up because she had 'Cruella de Ville' this morning, so she had to behave. As she got [patient name] up, she sang the song 'Cruella de Ville, Cruella de Ville' to her, to which I heard [patient name] giggling. H/RO continued this fun with [patient name] for the remainder of the shift, catching her eye when she was looking quiet and subdued and singing 'Cruella de Ville' to her, or singing it in the background when [patient name] wasn't looking, causing [patient name] to look up, smile and search the room until she found H/RO. (Fieldnote, Ward C)

Staff also employed spatial management strategies to avoid accidents, diffuse potential conflicts, and decrease stress levels. These strategies primarily involved moving patients to different dayrooms (Ward B) or to 'quiet areas' on the hallway (Wards A and C), separating those who were engaging in overly intimate or potentially discordant ways, using restraining belts to secure individuals at risk of falling, and monitoring the movement of others.

In some cases, the HCAs' reflections revealed considerable awareness about the trade-offs they had to make between individual and group needs. Some suggested that the satisfaction of group needs justified less-than-ideal decisions regarding the individual. The following fieldnote contains one researcher's own reflections about such difficult trade-offs:

The patient stayed at the bottom of the corridor on a sofa for the remainder of my shift. Yes, it sounds mean even as I write it, having been there, but at the time it was the only place to put her to prevent her shouting at staff and other patients – the patient talks so loudly and monotonously that when she just talks to other patients they think she is threatening them to retaliate. (Fieldnote, Ward C)

Another aspect of 'organising care' which deserves particular attention is the management of ward routines.

5.3 Working within ward systems

As noted in Section 3, the extent to which staff work within a routinised care structure varies across the three wards; that is, at the time of the study, care on Ward A was considerably routinised, whereas on Ward B there was a more explicit commitment to flexibility and patient choice, and

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a more routine approach was being implemented on Ward C as we concluded data collection. Notwithstanding these variations in approach, there remained a substantial degree of structure to the activities conducted on *each* ward, which had important implications for the HCAs' role. Although not responsible for their design, as mentioned above, the HCAs nonetheless constructively engaged with such structures.

We found, for instance, that some HCAs used their 'emotional labour' to translate institutional routine into a more personalised experience for the patients. Introduced by Hochschild (37), the concept of emotional labour refers to the ways that paid staff manage their emotions in order to create an appropriate emotional climate for their clients or, in the health care context, their patients. For example, one researcher wrote:

I noticed H/CE using a very courteous style with the patients when he was helping them up after the meal – saying 'thank you for coming, ladies' as if he were the maitre d' of a posh restaurant. (Fieldnote, Ward A)

While fulfilling his formal duty to accomplish the mealtime routine in a standard and efficient manner, H/CE enhanced the patients' experience in this example by treating them as independent individuals who had freely chosen his service, rather than hospitalised patients dependent on his care. Without affecting the objective circumstances, that is, the HCA used his emotional labour to enhance the self-esteem and wellbeing of the patients.

Invoking their practical autonomy, the HCAs also made minor adaptations within routines to suit individual patients. For example, medications were administered to all patients at approximately the same times every day on each ward, rather than being doled out individually; this ensured that every patient received his or her medication, as well as conserving staff time. However, within this routine, HCAs who were 'running' the medications would often make small concessions, for example by taking extra time to gain the trust of individual patients.

Evidence from long-term care institutions and hospice care suggests that routines can offer a positive framework for care, provided that staff are skilled at judging how to personalise care within their parameters (11, 36, 38). Our observations suggest that HCAs play a critical role in transforming routine expectations into personalised care.

5.4 Flexibility and energy rationing

Finally, a strong message articulated by the HCAs was that their work is varied and unpredictable, requiring them to be constantly responsive and adaptable.

*The setting always stays the same but the patients always change, so the job is always that little bit different day-to-day. That's how I see it anyway, the job is always different because from each day, yesterday was a bad day, today is a good day, I don't know why but you know, the patients just seem to be a bit different than they were yesterday … but they are the same patients. (*H/PN, Ward A)

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At certain times, balancing the needs of this diverse and often volatile patient group required significant competence in multitasking and a high level of alertness:

No sooner had H/GL sat down to continue his notes, than was the patient back up again playing with the television wires. H/GL again had to leave his notes to see the patient. Staff seem to have to be constantly aware of the surroundings and almost be in two places at once. (Fieldnote, Ward C)

HCAs also multitasked when taking their official breaks in the dayroom, keeping their attention on the patients while also eating their own meals and 'switching off' to a limited degree from the pressures of their role. At other times, they varied their level of responsiveness according to who else was present, taking advantage of attentive visitors to enjoy some downtime:

Part of the time I just stood back at the kitchen island, looking out over the dayroom, noting how H/HN and H/SN seemed able to sit unruffled in the midst of all the activity of visitors, TV, and wandering patients. They didn't keep hopping to attention the way I was inclined to. (Fieldnote, Ward A)

In other words, part of the HCAs' remit in managing the ward environment entailed managing their own energy outlay, in order to conserve energy for the busiest times and thus avoid stress and burnout. The effort expended on a given task was influenced by the likely demands of the shift overall, a lesson which had to be learned by newcomers to the ward (such as the researchers):

We've all got different work to do because we've got a lot of aspects to our work… There is always something to do, so most of the time we've got a pretty full ward and then obviously you might get five minutes to sit down and have a quick chat with your colleague, and you need that little bit of a sit down for five minutes and a bit of a break before you have to get up and start again, do you know what I mean, just little tiny breaks that might save you a little bit. (H/CE, Ward A)

Appearances can therefore be deceptive on these wards. If staff are sitting down, they may be recovering from a physically demanding episode or about to engage with a challenging patient. Visitors to the ward, such as patients' families, may not be aware of how HCAs actively ration their emotional and physical energy over the entire shift, and this can lead to misunderstandings.

5.5 Interacting with families

Another aspect of their distinctive role came into play during visiting hours on the ward, when HCAs acted as mediators between informal carers and the formal care system. Although the qualified nursing staff communicated with relatives on medical matters related to diagnosis and treatment, the HCAs provide a valuable direct link to the patients. We observed that HCAs were best placed to update relatives on the daily details, such as how much patients slept, what they ate for dinner, whether they had been distressed,

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and so on. They could offer advice and assistance on practical matters and model effective responses to challenging behaviours, including the use of humour in all its guises. In these ways, HCAs cared for relatives as well as patients, potentially helping ease their adaptation to the formal care context. However, such interactions between family carers and HCAs were not the rule and some HCAs actively avoided contact with relatives.

In their interviews, many HCAs reported that communication with relatives was an important part of their role. This was an area of complex emotions, however. It was widely recognised that many relatives feel guilty handing over care to others and/or grief at the separation from their loved one. In addition, they may feel threatened or scared by the unfamiliar and often hectic ward setting. Relatives may believe that staff cannot provide the same standard of individualised care that was given at home, and they may also be unaware of the competing demands on HCAs. Consequently, relatives may often be critical of HCAs. We found that emotional labour was demanded of the HCAs in order to address relatives' concerns without becoming demoralised by their critiques:

You know, they might be a bit snappy or looking for something and they can't find it, it's generally over something petty really, and I think they realise it themselves after, you know, some clothes or something have got missing, they can be a bit snappy sometimes… I always say, 'Well I'll have a look and let the other staff know on the next shift, but I'm sure it will come to light, I'm sure you will find it,' and then they will come to me on the next shift or the day after and say, 'I found his glasses, you know you said we'd find them and I found them,' and I say, 'I know, it's just how it happens on here,' but they're quite pleased then – and it's all forgotten then, you see. (H/AN, Ward A)

This emotional labour goes beyond the desensitisation strategies described above; it requires active empathy on the part of the staff member and the suppression of their own natural reactions to criticism in order to offer a response that is conciliatory and constructive. These findings support those of Ward *et al* (36), who observed the importance of communication skills which go beyond 'getting the job done' and enable the maintenance of relationships with people with dementia. Building on this, our findings suggest the importance of maintaining relationships outside the immediate patient-carer dyad, which we discuss in more detail in Section 6.5: *Relationship-centred care*.

5.5.1 Support

An inpatient dementia care ward can appear daunting and distressing, particularly to someone who must leave their parent or partner there. HCAs worked to manage these impressions in order to reassure relatives about the quality of care their loved one is receiving. Some of their work involved challenging preconceived notions about hospital care that derive from past experience or media reports:

It was in the media not long ago, staff abusing people in nursing homes and not treating their relatives right in nursing homes, well that is still kind of

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spilt over into the hospitals in the NHS where families are just walking onto the ward thinking that you're abusing their relatives or not doing the job right or they don't understand the scenarios that we're in and how we're treating the patients and why we're doing this and why we're doing that. They're constantly watching us under suspicion. (H/CE, Ward A)

HCAs also endeavoured to control the kinds of patient activities and behaviours which may be quite shocking to visitors, making the ward atmosphere more socially acceptable:

We have visiting times in the afternoons, it's better in the afternoons because the visitors, the dayroom, the dining room is purely for the patients, they've got a private area because you have got some people that are sexually disinhibited, i.e. they'll just, they don't realise what they're doing, they just take their top off, they could be warm, but it's not fair for other relatives to see. (M/BU, Ward C)

Staff sometimes socialised with relatives as well, fostering the kind of meaningful social connections which provide some mutual relief from the intense challenge of engaging with cognitively impaired patients. There are parallels here with the social dimension of team working. One researcher deliberately relaxed their own approach to socialising after observing that the other staff, rather than treating relatives with exaggerated caution or deference, understood that 'chatting with some of them is actually a feature of the job' and did so in 'a quite relaxed and straightforward manner':

There ensued a lot of banter between the patient's husband, H/SN and Q/CR; he appears to enjoy a very jovial relationship with the staff, now that he's become such a regular visitor to the ward and because the patient has improved so dramatically. 'Hey, talk to the organ grinder, not to the monkey!' said Q/CR tartly when he complained about a certain regulation, and at another point he touched her on the arm then jumped back saying 'oh, barrier, barrier, no touching the staff!' H/SN joked at a certain point: 'You love coming in to see us, let's face it'. (Fieldnote, Ward A)

Sometimes these situated connections produced meaningful attachments which extended beyond the boundaries of the wards, for example:

Yes, you quite often get attached to the relatives, because they'll talk to you, they can have a full conversation with you, they can tell you what that person was like that you're looking after, you'll find when you're looking after people long term, and even out of work when you see them, 'oh hey-up, are you alright?' After the person has probably died, they still speak to you when you see them, quite often. (H/T1, Ward C)

Sometimes reconciling visitors' needs to be reassured that their particular loved one is receiving the best possible care and the demands of the institutional care context seemed almost impossible, however:

The personal carers want a certain method of care, and a certain standard and sometimes there's a lot of complaints because their ideals and our ideals are different worlds apart, and that is because at the end of the day we're a small crew and we're managing not just their relative, we're having

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to manage a ward of patients, so it's a different, you know it's a different programme, it's a different … it's a lot more difficult, where, when somebody's being cared for at home, it's very one-to-one, it's very personal. When you've got five, six staff on, caring for 24 patients, I mean what have we got on at the moment, 22, 23 patients? It's a lot. (H/BN, Ward A)

In other examples, it was not as easy to interpret whether HCAs were making conscious choices between the competing needs of patients, families, and staff or whether they had simply become desensitised to their environment and the relatives' needs:

Whilst all this was going on, [patient A]'s monotonous and loud voice resonated in the background. Also, [patient B]'s relatives had come to visit and were witnessing all this. This made me feel so uncomfortable for them, but I didn't see this obviously in other staff. When [patient A] quietened down a little I sat near her so that I was in between her and [patient B]. [Patient A] was now shouting at [patient B]'s relatives to get out her house and leave. (Fieldnote, Ward C)

5.5.2 Knowledge transfer

Informal carers can provide HCAs with insight into the patients' personalities and history, and HCAs can update informal carers on daily progress as well as helping them understand and adjust to the hospital context (39, 40). Evidence suggests that this 'knowledge transfer' helps formal carers to 'identify meaningful activities or to personalise care routines', in other words to enhance individual patients' care (38).

HCAs acknowledged that sharing information with relatives can enable better understanding and management of patients:

I do like to talk and I like to know more about the background of the patient and that and what their hobbies were and then you know how to talk to them. (H/BC, Ward A)

However, this important process of knowledge transfer is often eclipsed by immediate care tasks. For example, Q/NN described how the 'life history books' had been discontinued on Ward B despite their usefulness:

[The life history] was a book we put together full of questions that we gave to relatives for them to fill out. It was basic stuff: what's their favourite colour and what sort of films do they like lots and lots of questions like that, and from that book you could get a good picture of their background and what sorts of things they like to do and don't like to do. … We've had a couple of admissions recently and we've got a lot of information from the relatives, I think that's because we've pushed, the HCAs have, and got a lot of the information ourselves, but if we could get the history books as part of the package – 'here's some information on the wards and here's a book for you to fill out' – then it would be a lot better. (Q/NN, Ward B)

In contrast to the scenario above in which staff apparently 'pushed' for more information, in many cases HCAs did not appear to avail themselves

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of opportunities to engage in knowledge transfer with informal carers, even when the opportunity arose. We argue that this limitation must be understood in light of the HCAs' generally devalued role, consequent low self-esteem and their tendency to build strong group boundaries against external 'threats'. This theme will be introduced below and explored further in the third section.

5.5.3 'Us' versus 'them'

In their front-line position, HCAs can become the initial target for expressions of the negative emotions that relatives bring to the ward – emotions such as loss, guilt, fear, bewilderment, sadness, disempowerment, and anger. In their interviews, quite a few staff expressed frustration about being criticised by visitors over relatively minor issues like missing socks, without reciprocal recognition of the myriad other issues they *do* deal with behind the scenes:

INT: How do you find relatives when they are around here?

RES: Some of them are absolutely lovely, they understand what they're doing but some have been up against everything, they've wanted everything their way at the expense of other patients, they just want to control things.

INT: I mean it's a lot to let go, I guess, for them.

RES: Yeah, but it doesn't make it any easier when you're dealing with complaints like about your staff team. (H/AI, Ward B)

The HCAs' response, therefore, sometimes involved the deliberate deflection of criticism from visitors, which yielded the strained, or at least guarded, relationships that we sometimes witnessed. We observed that one of the HCAs' tactics was to label relatives as 'good' or 'bad', the good ones being those who listened to HCAs' reasoning and the bad ones those who confronted staff. In the following example from Ward C, in which H/HA tells fellow HCAs about a patient who used a walking frame as staff took him to the toilet, two sisters from the same family exemplify the opposing ideal-types:

He had started to walk out and 'flopped' to the floor, laughing at staff as they tried to get him up and not helping them. H/HA told us that his relatives were annoyed and one of them in particular was very rude to staff; she called her the 'gobby' daughter and the other daughter the 'nice' one. The gobby daughter had complained that this is why they couldn't cope at home, that he used to do this frequently. H/HA told the daughters that they couldn't deny him use of the frame, as physio have recommended it for his improvement in strength and walking skills. H/HA told us that she had spoken quite firmly to the daughter, who had not seemed happy at all. H/HA said that the 'nice' one listened more to staff's views. (Fieldnote, Ward C)

Existing literature suggests that, on the other hand, informal carers 'often face a host of uncertainties about which new roles to adopt and how to

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interact with staff' (39). Similarly, in the focus groups we conducted, informal carers indicated that they found it difficult to know how to best approach HCAs without seeming critical or interfering and thus encountering defensive responses.

5.5.4 Scope for greater involvement with families?

We found that the HCAs' distinctive role with regard to patients' families had three main aspects: providing practical and emotional support, facilitating knowledge transfer, and maintaining group boundaries. Occupying these pivotal positions, HCAs could, if they wished, play a key role in mediating between informal carers and the institutional context. However, the relationship between HCAs and patients' families was often fraught with tension and conflict.

Our observations lead us to wonder whether more could be done to afford HCAs and informal carers sufficient time and encouragement to develop mutual trust and understanding so that their complementary knowledge may benefit patient care (38, 41).

5.6 Bonding and supporting the team

As discussed in previous sections, the sociable team environment was key to the promotion of wellbeing among the HCAs on these wards, which in turn impacted on the patients' quality of life. This environment did not occur naturally, however: it was strengthened and sustained through the proactive efforts of the HCAs.

Our findings demonstrate that, bearing in mind patients' needs in most instances, ward staff took opportunities to enact and strengthen their interpersonal relationships through 'socialising' at different points throughout the shift, including after handover, while working with individual patients, during routine downtimes on the ward, and during formal and informal breaks. By telling and retelling stories with different coworkers throughout the day, providing cups of tea at opportune moments on shift, reinforcing personal affection, and so on, the HCAs created an environment of enhanced wellbeing for staff and this, in turn, encouraged individual workers to bring a positive and productive attitude to their direct care responsibilities. This is an additional aspect of their distinctive contribution.

Of course, there were occasional exceptions where the carefully-maintained balance between investing in the team and providing patient care shifted in favour of the team. In these moments, we observed that the patients figuratively receded into the background while staff brought their own socialising to the foreground. Some staff registered awareness and disapproval of this tendency in their interviews:

W*e don't get paid to socialise, it would be nice to come to work and sit around and chat but are we working towards anything, are we doing more for the clients? You might miss out on something just by concentrating on one thing and forgetting the clients.* (Q/ZR, Ward B)

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There are certain ones that stick together and I like to have fun, yes, but I also think that the care should come first and they like to chit chat first, yes, no matter what goes on, so I just stop with the patients, there is not much you can do on your own as you know, but I just do what I can. (H/BC, Ward A)

5.6.1 Practical support

To the untrained eye, countless tasks are accomplished throughout each shift with little delegation or even discussion about who will do them and when. On Ward A, for example, routine dictated that the HCAs' first tasks of the day were to rouse, bathe, and dress every patient, one by one. The simultaneous division of labour and co-operation that this required seemed to occur naturally, however – an unspoken choreography simply unfolded. As stated already, HCAs exercised considerable practical autonomy in organising care within these routine parameters; an added dimension is that they did so in apparently implicit agreement with the entire team. Our sustained observations revealed that HCAs put quite a lot of unacknowledged work into ensuring that tasks were accomplished in a logical, efficient, and equitable manner:

Within the team, everybody has to do something, I mean it's like in the morning, we're all off, there's patients to be assisted in getting washed and dressed, and everybody does, so I mean I'm a fair person, I like to see that we all work together and the duties should be shared out, it shouldn't just be one person in the team, and people should, you know, if somebody's struggling there should be … if they notice that somebody is struggling, they should be there at the side of them saying, 'do you want some help?' Because there's nothing worse than struggling, and if somebody is struggling they should have the knowledge to ask for help. (H/BN, Ward A)

Staff kept tabs on each other. If something took longer than expected or a staff member was out of sight and presumed to be having problems with a patient, the others would mobilise. As they shared tasks, the HCAs also made adjustments to accommodate others' past experiences or idiosyncrasies, protecting each other as noted in Section 4: *Team working*. HCAs also policed their collective employment rights by ensuring that no member of the team missed a break nor was required to stay a moment past the end of a shift:

[… I felt completely drained, with my patience almost used up – and was so ready to be dismissed.] I took the patient's arm and walked with him to the toilet. A couple of minutes later, H/CE came into the bathroom, wearing his street clothes, to tell me the night staff had come out. I sort of gestured toward the patient, asking whether he's okay on his own, and H/CE turned toward him, asking '[patient name], are you nearly done – or just starting?' When he replied that he was just starting, H/CE said to me, 'come on, we'll get one of them to take over,' and led the way back to the day room, going straight over to where the staff were gathered to ask one of them to check on the patient. (Fieldnote, Ward A)

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In this example, the researcher was struck by the extent of a coworker's solicitude: rather than leaving directly, H/CE had taken the time to ensure that the researcher was free to leave at the right time along with everyone else. Further, the divisions between different shifts which were mentioned earlier (primarily between day and night staff) did not prevent demonstrations of empathy and co-operation between HCAs on one shift toward another:

When I asked H/SS how things had been with her, she pulled a face to suggest that they'd been quite challenging. She went on to tell me about how, when she came in to work a few days ago, she opted to skip handover and take over supervision of the dayroom so that the 'nursing assistants' (as she called them) from the late shift could leave a bit early; she did that because, as she said to me with great emphasis on the words, 'they looked so stressed'. 'They looked,' she said, then started to get to her feet, 'wait, I have to demonstrate' – and stood up next to her chair, hunching her shoulders right up to her earlobes and adopting a tense expression. (Fieldnote, Ward A)

Group norms are often thrown into relief by the exceptions, and infrequent failures to take into account 'the team' tended to draw criticism from other staff. For example:

You've just got to get one or two who can't be bothered and it just brings that team right down and you've got to do that extra work and if you pull together it makes the job a lot, lot easier – a lot easier – so you might as well just get on with it. (H/SN, Ward A)

HCAs often referred to the team as family and, while the *structure* of the team was formally defined, its *value* as a vehicle for trust, security, support, and esteem had to be constantly reinforced by the staff over the course of every shift. Even making cups of tea and coffee was an important 'team-building' activity – as H/BN informed the researcher midway through the first shift – because it symbolised supporting one another on the job.

In summary, the HCAs invested considerable energy into gauging the needs of their fellow team members, providing support as needed and seeking support when appropriate. This mutual assistance was critical to the smooth functioning of the ward and the ability of each individual to provide high-quality care.

5.7 Conclusion: expanded scope of the HCA role

The evidence presented in this section suggests that the formal HCA role as direct provider of patient care lies at the heart of a broader but largely unacknowledged role as 'manager of the ward environment'. In that broader role but within the constraints of ward routines, HCAs regulate the emotional climate and enhance the ward atmosphere through the organisation of care. They promote individual patients' quality of life while also taking into consideration the needs of the patient group overall, ward visitors, and the staff team.

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To maintain this difficult balance, HCAs marshal a range of resources, including their firsthand knowledge and experience of the patients, their physical and emotional labour, the practical and emotional support of coworkers, the framework afforded by ward systems, the physical environment of the ward, and their pride in the ascribed moral purpose of their role. Our findings fully support the assertion that:

The running of the wards is down to the HCAs, mainly… It's because we understand the patients a lot better than management do because we're hands on. We know exactly what's going on, we know exactly why he's doing that. (H/IN, Ward B)

In the following section we review the policy guidance which underpins workforce training and development and the notion of person-centred care in dementia, focusing in particular on HCAs. This leads to a discussion of the applicability of person-centred care to the specific research settings.

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6 Policy informing HCA practice

In this section, we locate our findings in relation to national policy and related documents on dementia care over the past decade. The study reported here was designed to improve understanding of nonqualified dementia care staff working in NHS wards. We studied three wards for the assessment and treatment of dementia. Our data are therefore limited in scope, so we do not attempt to reconcile policy with practice in any general sense; rather, we use the policy heuristic to interpret some of our findings.

6.1 Relevance of policy to HCA practice

Most policy in the health care arena seeks to influence, from the top-down, the organisational direction of travel. Ideally, such policy is in turn articulated through local strategy, management goals, and/or staff training and guidelines. The assumption is that policy will ultimately influence, implicitly or explicitly, the priorities of front-line staff. Therefore, it would be naïve to expect national policy documents to *directly* influence the day-to-day practice of HCAs or indeed any other staff. We have seen that HCAs exercise considerable autonomy in determining the ways in which older people with dementia are cared for in hospital settings. Here, we seek to identify how key policy concepts were interpreted and manifested in the values, approaches and attitudes of the HCAs whom we studied.

By 'policy', we mean governmental guidance about services for people with dementia, including national strategies and service frameworks. Two policy streams are pertinent to our subject: the first relating to the care of older people with dementia and the second relating to the workforce who provide this care. Given the focus of our study, we highlight in particular any references to the nonqualified workforce, which is dominated by HCAs. We also review select publications which inform or evaluate the implementation of national policy.

The second part of this section identifies the values and principles enshrined in policy which underpin the care of older people with dementia and which are embodied in the concept of person-centred care. Turning to our data, we illustrate how we observed person-centred care to be enacted and understood by HCAs and consider what a *relational* understanding of the care process may bring to this analysis. Finally, we discuss what further policy developments may help to achieve a coherent and evidence-based framework for the understanding and improvement of dementia care at the front line.

6.2 Health and social care policy context

Living Well with Dementia: A National Dementia Strategy (2), which was introduced in Section 2, has its origins in a number of initiatives around mental health services for older people in the past decade. These include

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policy statements, reviews of practice, and recommended standards for service delivery and staff capabilities. The following sub-section will outline those initiatives chronologically, briefly drawing out the elements that are particularly relevant to the working context and conditions of HCAs on inpatient dementia care wards. Section 6.3 will then do the same in relation to NHS workforce policy.

Forget Me Not: Mental Health Services for Older People (42), reviewed services for older people with mental health problems (particularly dementia and depression) across the public sector in England and Wales, focusing particularly on structural issues, namely: types of service delivery; communication and co-operation between agencies; and strategic planning and commissioning. Although saying little about front-line staffing, the report did make recommendations for improving the ward environments which constitute the context of HCAs' work.

The *National Service Framework for Older People (NSFOP)* (3) was developed through consultation with health professionals, service managers, voluntary agencies, patients, carers, and other stakeholders. Like previous National Service Frameworks (NSFs), it set out evidence-based quality requirements and related strategies for care provision. With relevance to this study, the NSFOP emphasised: responding effectively to individual needs; taking account of social and cultural factors affecting care experiences and outcomes; and providing information, advice, and support for carers as well as service users. Standard 7 of the NSFOP specified the need for comprehensive specialist mental health services for older people which, with respect to dementia, entails early diagnosis and treatment as well as the provision of high-quality health and social care through every stage of the illness. Early diagnosis and treatment was taken up as a key focus of the *National Dementia Strategy*.

In 2004, the Department of Health released *Better Health in Old Age* (43), a resource document on the NSFOP targeted at health and social care staff, which stated that 'mental health services for older people need further attention' (43) but provided no related recommendations with specific relevance to the dementia care workforce. Other reports, including *Improving Older People's Services: An Overview of Performance* (44), *What CHI Has Found in Mental Health Trusts* (45) and *Living Well in Later Life* (46) also documented deficiencies in the commissioning and delivery of mental health services for older people.

Securing Better Mental Health for Older Adults (47) addressed the evidence that improvements in care for younger people with mental health problems had not been matched by parallel improvements for older people. It advocated a partnership approach across mainstream and specialist mental health and older people's services. *Everybody's Business: Integrated Mental Health Services for Older Adults* (48) was published as an implementation plan for the principles promoted in *Securing Better Mental Health for Older Adults*. Aimed at 'improving health and social care practice at the front line' rather than introducing new policies, this document described the key elements of comprehensive mental health services for

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older adults. Relevant recommendations included: respecting the unique qualities of each individual when planning and delivering care; ensuring that staff at every level of care are trained to communicate effectively with service users and carers (with regard to ethical issues such as consent); and enabling service user and carer involvement in care delivery. *Everybody's Business* was endorsed by the 2006 White Paper on community services *Our Health, Our Care, Our Say* (49) and the 2006 NICE/SCIE guidelines (50) on the treatment and care of people with dementia in health and social care.

Who Cares Wins: Improving the Outcome for Older People Admitted to the General Hospital (51) provided guidelines for the development of liaison mental health services for older people in general hospitals. It called for development of specialist liaison services to deal with the challenging clinical issues surrounding mental illness in elderly populations within general hospitals. It recommended that commissioners and providers of health and social care should review the care of older people in general hospitals with mental disorders and work toward improving outcomes by developing liaison-style services.

Raising the Standard: Specialist Services for Older People with Mental Illness (52) presented the components of a comprehensive specialist service. It was endorsed by Age Concern, the Alzheimer's Society, the British Geriatrics Society, National Older People's Mental Health Programme Care Services Improvement Partnership, and the Royal College of Nursing. Complementing *Everybody's Business* and *Who Cares Wins*, *Raising the Standard* advocated close co-ordination between specialist psychiatry services for older people and generic services in the community. The underlying principle was that 'older people should have the same rights as all adults, particularly where, due to mental illness, their rights to dignity and respect are threatened'. To achieve this, 'scrupulous monitoring against standards of good practice is required in all settings where older people are cared for. Without this, there exists the possibility of a culture of patient care that does not recognise abuse in its many forms'. This document recommended training in mental health of older people for all health and social care professionals, including those working in settings that do not specialise in caring for older people, such as general hospital staff.

About a decade ago, the development of pharmaceutical medications which delay early stages of Alzheimer's disease led to a great deal of interest in treatment options, suitability of treatments, and costs. A national prescribing policy was sought to resolve some of the questions raised. Developed partly in response to this interest, the NICE/SCIE *Guideline on the Treatment and Care of People with Dementia in Health and Social Care* (50) nonetheless went much further than medication. It stressed the need for early identification and intervention in dementia and called for an effective response across the range of severity and complexity of the illness (including the incorporation of a palliative care approach from the point of diagnosis onward). Relevant to the focus of the present study, with regard to 'behaviour that challenges', for example, the guideline recommended early assessment and identification of the factors that may generate,

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aggravate, or improve such behaviour in order to design individualised interventions. These recommendations were echoed in the 2009 Department of Health report (53), which criticised the use of anti-psychotic medication to control the behaviour of people with dementia. The report recommended the development of appropriate skills for care staff in the non-pharmacological treatment for behavioural disorder.

Dementia UK: The Full Report (54) was commissioned by the Alzheimer's Society to evaluate the social and economic impact of dementia. It concluded with a series of recommendations, among them: making dementia a national priority; improving dementia care skills; and developing comprehensive dementia care models.

Improving Services and Support for People with Dementia (55) followed in the footsteps of *Forget Me Not* in assessing the quality of care received by people with dementia and their families. It highlighted inconsistencies in specialist provision and found that the competence of GPs in diagnosing the symptoms of dementia had not increased. The report concluded that dementia services were not delivering value for money to taxpayers, nor people with dementia and their families. The NICE guideline and the NAO report together marked a shift of focus in dementia care policy from public services dealing mainly with late stages of the disorder to early diagnosis and intervention, with more support in the community for people with dementia and their families. This is embodied in the *Living Well with Dementia: a National Dementia Strategy*, which sets as Objective 8 improving the quality of care for people with dementia in general hospitals: 'Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals'. Specialist mental health provision of dementia wards like those in the present study (as opposed to general hospital provision) appears to be somewhat peripheral to this objective, although such wards are clearly a step on the dementia care pathway to which it refers.

The focus of current health and social care policy rests squarely on caring for people with dementia in the community and in general rather than psychiatric hospitals. While the intention may be to minimise unnecessary admissions, this policy emphasis tends to support the impression, conveyed by staff included in this study, that the care provided on specialist dementia wards is largely hidden and unappreciated. As most people with dementia may never require admission to such wards for assessment or treatment, the treatment of those who *do* enter specialist wards is not addressed in *Living Well with Dementia*, except to note the National Audit Office objective of minimising length of hospital stays to reduce costs. However, the *National Dementia Strategy* and other policy documents rest on a number of principles which are common to all aspects of dementia care, which we review below in Section 6.4 on person-centred care.

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6.3 Workforce development policy

In parallel with health and social care policies focussing on mental health or dementia, there have been a number of initiatives directed at the health care workforce which are also relevant to our understanding of the current role of HCAs. *Essence of Care* (56), which was launched in response to national variations in nursing care standards across all patient groups, is a national strategy for improving nursing care through best practice. It included a number of benchmarks identified by patients and carers as critical to their experience of care: the care environment; communication; food and drink; personal hygiene; pressure ulcers; bladder and bowel care; promoting health and wellbeing; record-keeping; respect; safety; and self-care. These benchmarks are clearly relevant to HCAs' day-to-day work, and we found that there was awareness of *Essence of Care* among some of those whom we observed and interviewed.

The National Mental Health Development Unit, the agency charged with the development of materials to support policy implementation, and the Department of Health produced *Let's Respect* (57), a toolkit aimed at health care staff working with older people with mental health needs, particularly those in acute hospital settings. Through images, case studies, and practical guidance, *Let's Respect* sought to raise health professionals' awareness of mental health issues in older people and equip them to address these issues more confidently.

The *New Ways of Working* pilot programme (58), which was operating in the host Trust at the time of our study, was launched to help mental health care teams achieve their maximum potential. Components of the programme include: leadership based on ability and competence (rather than status); distribution rather than delegation of responsibility; matching skills to the needs of service users and carers; individual responsibility for clinical governance standards; delivery of care through a team approach; attention to efficiency in the delivery of care; and effective and intelligent management of caseloads. The programme particularly acknowledges the 'important, substantial and sometimes under-recognised contribution to services' made by nonqualified staff, who 'often spend more direct time with service users than staff with traditional professional qualifications'. With regards to HCAs, *New Ways of Working* recommends that issues of role definition, accountability, education and training, and supervision be addressed.

Prepared to Care: Challenging the Dementia Skills Gap (22) made an important contribution to workforce policy in relation to HCAs, as it examined recruitment, recognition, training, and retention of the dementia care workforce. Overall, the report concluded that there has been little priority placed on developing a workforce with the appropriate skills to provide high-quality dementia care due to the 'mistaken, but lingering, belief that attempts to improve wellbeing in people with dementia are hopeless'. It found that low status, poor employment terms and conditions, and lack of career opportunities have led to increasing staff turnover and decreasing investment in workforce development. The low status of

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dementia care work was attributed in part to the lack of formal recognition of key caring attributes, such as warmth and empathy, as discrete skills or capabilities.

Prepared to Care also recommended that the Department of Health should prioritise early work on Objective 13 of the *National Dementia Strategy*, which states that '[a]ll health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia'. *Prepared to Care* framed our data analysis in terms of key workforce issues: skills, career structure and recognition of HCAs.

6.4 Policy and practice of person-centred care

Evidence from one ward suggests that the *New Ways of Working* approach helped increase the support and recognition of all members of the health care team, including the front-line staff. As part of the pilot programme, the team took part in away-days and drew up an action plan which involved changes to processes and existing roles and the development of new roles. We observed that, of the three sites studied, staff on that ward took the most active and confident role in nursing tasks. We also found that taking on more clinical responsibilities seemed to increase the HCAs' sense of job motivation and satisfaction. In these respects, *New Ways of Working* did seem to be making a difference. Because staff rarely referred explicitly to the programme in field observations or interviews, however, the specific impact of *New Ways of Working* on their morale and motivation requires further investigation.

The health and social care policy documents reviewed in Section 6.2 were primarily concerned with the organisation and delivery of mental health services for older people outside of hospital. However, the underpinning principles and values are also applicable to the care of older people with dementia in hospital settings. The NSFOP provided some core themes: responding effectively to individual needs; taking account of social and cultural factors; and providing support for carers as well as service users. These are reiterated in a slightly different form in *Securing Better Mental Health for Older Adults* as: respecting the unique qualities of each individual; ensuring that staff at every level are trained to communicate effectively; and enabling service user and carer involvement. *Essence of Care* talks about privacy and dignity, while *Raising the Standard* brings in the concepts of rights and respect due to older people with mental health problems, which are echoed in the *Let's Respect* toolkit. Taken together, these themes reflect an understanding of older people with dementia which is situated in their family context, takes into account the whole person, and endorses their inherent value as human beings regardless of any mental health problem. This approach is encapsulated in the notion of person-centred care, or individualised care, as described below.

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The terms 'personhood' and 'person-centred care' were first used in relation to dementia by Tom Kitwood in the 1980s. The primary goal of person-centred care, which offers a 'psychosocial approach' to dementia care, is for people with dementia to maintain their personhood in the face of failing mental powers (59, 60). This is only possible when the psychosocial needs of people with dementia are sufficiently met. In order to provide a succinct and up-to-date definition of person-centred care, Dawn Brooker (59) developed the approach into the following equation: Person-centred care = V + I + P + S, where V represents valuing people with dementia and their carers, I represents treating people with dementia as individuals, P represents taking into account their perspective, and S represents promoting a social environment that supports their psychological needs.

The term person-centred care was not necessarily familiar to the HCAs we interviewed:

INT: If I say person-centred care to you, what does that mean?

RES: Personal...?

INT: Person-centred care.

RES: Person-centred care? Damn, you know, I know the definition of person-centred care as well and do you know what, I can't remember it for the life of me, it's not up in this room anywhere is it? You took it down!

INT: No, does it give you any kind of like feeling or just anything at all, any reaction to that idea?

RES: Person-centred care, I know, you see everyone is different so … so I suppose it could be like the individual's needs sort of thing, because patient A will be totally different to what they need to what patient B will be like, so I think in a way it will be that sort of thing. (H/PN, Ward A)

When probed, one respondent seemed quite uncomfortable expressing views about person-centred care:

INT: So obviously person-centred care is what we are supposed to be working to, what does that mean to you?

RES: I've got no idea, I just come and do my job the best I can.

INT: And how is that?

RES: Just to make sure they don't need anything and they're comfortable or as comfortable as they can be in such a place, that's it, I don't know about person-centred care; that is what I do. (H/AI, Ward B)

However, many HCAs appeared to have internalised the concept of person-centred practice without explicit reference to the theory, as suggested by the following interview excerpt:

One thing that does annoy me, I forgot about it, was when people talk to them as though they're children. They're not children, they're adults. That particular lady I was telling you about, it takes her a while to process what you've said to her, and if you say something else to her too quickly she'll

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say 'oh it's all gone wrong, it's all gone wrong'. You give her some time to answer you and she usually does, bless her. (H/GL, Ward C)

For others, considering person-centred care provided a new dimension to their work:

I don't think anybody would know the illness would affect people so differently. I mean we are tarring people with the same name but everyone is individual. It's quite a nice way of seeing it, the individual care – before it was just a task job, now it's not just a task job. (A/LP, Ward B)

Whether or not staff used the terminology of person-centred care, the framework helps explain the motivation behind some of their interactions with patients which might otherwise seem strange or inappropriate. Taking a person-centred perspective also highlights exceptions to the generally high standard of care that we observed, as in the following example:

H/HN sat next to [patient name], who was saying in her loud voice 'I'm frightened to death in here' and other repetitive things – ignoring her at times, then at others saying to her quite dismissively that she needn't be frightened, that we've been nothing but good to her in here. (Fieldnote, Ward A)

Our observations supply ample evidence that HCAs face considerable obstacles to providing person-centred care and that the ideal may not be attainable in these settings all the time. First, it may be very difficult at times to identify the patients' individual needs, given the limits of their cognitive and communicative capacity. Second, as suggested in Section 5, HCAs must constantly juggle individual needs against group outcomes – which can sometimes entail choosing *against* person-centred care priorities, in the interests of fulfilling daily routines or maintaining relative stability across the ward. Such instances illustrate the potential for the individual needs of residents to be 'substituted by the value attached to physical and social order' (36).

The realisation of concepts of privacy and dignity in dementia care settings is affected by similar constraints, although staff retain or at least refer to them as ideals. The following fieldnote is from the researcher's first shift on the ward:

As she was talking, H/CY referred several times to patient 'dignity' and 'privacy' as the reasons for certain policies and procedures; at times this seemed naturally stated, at others as a directive from above. (Fieldnote, Ward A)

Over time, in practice, we observed that standards of privacy and dignity, like personalised care, were relative and negotiable, depending on many other factors in any given situation. One researcher concluded that 'dignity' often seemed to be interpreted differently from shift to shift and patient to patient.

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6.5 Relationship-centred care

Recent critiques of person-centred care approaches argue that their individualistic focus on autonomy and independence provides an inadequate model of care, especially within hospital settings (61). Instead, a model of 'relationship-centred care' has been proposed. The relationship-centred model of care retains the importance of respecting personhood but places greater emphasis on viewing the person within a network of social relationships which include the patient, their family, and staff at all levels. Importantly, the relationship-centred frameworks state that all those involved in caring should experience relationships that promote security, belonging, continuity, purpose, achievement, and significance (62, 63). This presents a distinct contrast to person-centred care approaches which, while recognising their importance, tend to consider staff only as a means to the end of individualised care (as judged ultimately by the patient) (5). When studying the relationship-centred framework in both inpatient and community care settings, Nolan *et al* (62) found that staff who felt valued and supported through resources, recognition, and training felt that they would be better able to value and support those in their care (63).

Earlier we summarised the vision of older people with dementia which is enshrined in health and social care policy as: situated in their family context; taking into account the whole person; and endorsing their inherent value as human beings. Without denying or diminishing the caring relationship, in which staff prioritise the needs of the cared-for person above their own interests, a relational perspective on the role of HCAs can be applied to our data. It balances the 'caring equation' by drawing attention to staff, as well as family carers, as human beings of inherent value with their own characteristics and social context, who play an active part in the caring process.

In a paper by Christine Brown Wilson, Sue Davies and Mike Nolan (38), three types of relationships in care homes were defined in ascending order of interconnection between participants:

- Pragmatic: Focused on the practical nature of caring, developed primarily through communications directly concerned with care tasks.
- Personal and responsive: Focused on understanding the resident as a person, developed through communications that involved social conversations with both residents and their family members.
- Reciprocal: Featuring negotiation and compromise, where the needs of staff, residents, and family members were taken into account in the context of a trusting relationship.

These types of relationships were observed in different proportions in three residential care settings by Brown Wilson *et al*, but they were not mutually

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exclusive. 'Residents in all three homes demonstrated the ability to become involved in and influence these relationships irrespective of their physical and cognitive abilities, but few residents were able to articulate fully how they developed relationships'. The researchers regard reciprocal relationships as the highest order, and consider that personal and responsive relationships are a necessary condition of reciprocal relationships. Their framework builds on earlier work which stresses the importance of 'empathic awareness' in care staff (39).

6.6 Application to the present study

What insights do our data offer when viewed through a relationship-centred lens? The researchers commented extensively on the satisfactions derived by HCAs from social interactions with coworkers, and the workers' motivations constitute a significant part of our interview data; these elements make up a vital part of the caring dynamic in the settings we studied. It is clear that HCAs gain emotionally from the caring role as well as giving to it, as they consciously and deliberately manage the environment and emotional climate on the wards. Although we only observed patients indirectly, we gleaned extensive evidence of relationships that were more than pragmatic from the interviews. These relationships were described by staff as forms of 'attachment', bearing in mind that attachment was somewhat selective:

INT: Do you ever get particularly attached to patients?

RES: Yes, yes, I always want to go and visit them but then I feel unfair on the patients that I wouldn't go and visit then. (H/SN, Ward A)

There are clear limits to the nature of the attachment: it stops short of a familial bond, which may be a way of managing one's emotional availability:

Like when it's your own family and it's your grandparents, my father-in-law died about, I think it's four years this year and yes I was very upset and it is really different when it's your own, I think you always keep that step between. (H/HN, Ward A)

One nurse was aware that certain staff tended to be more pragmatic in their approach to care (although this didn't rule out some degree of attachment as well):

I've worked with this particular lady for a long while and she always just… I'm not saying she didn't care at all about the patients, but she cared about herself more than she cared about the patients, it's her rights and her break and what time she finished and you know, etcetera. I mean, she was somebody I would say was coming for the money… I think she lost focus on the patients, she had more focus on herself than she did on the patients. She put something into the patients provided that she had all her needs met. (QM/DZ, Ward A)

The interviewees presented themselves as being in a relationship with patients, but one in which they have the upper hand; that is, the staff seemed to be saying that they were in control of the relationship and

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capable of setting its limits. Despite this, there were many examples in our fieldnotes of patients' behaviour having the power to affect staff. Apart from the positive emotional responses that patients elicited, which are discussed above in relation to attachment, there were many examples of behaviour with a negative impact on staff. In most cases, patients were not held to account for this behaviour so the negative effects were accepted as an inevitable part of the job. However, in a minority of cases, patients were deemed to know what they were doing, thus *deliberately* thwarting their carers or behaving in a generally antisocial manner.

This constitutes a fundamental difference between residential settings such as those studied by Brown-Wilson *et al* (38), where a significant proportion of residents retain moral responsibility for their actions and hence for their relationships, and the dementia care settings studied here.

The interpretation of our data suggests that 'relationship-centred care' is preferable to 'person-centred care' because it can accommodate staff-staff and staff-visitor care dyads, as well as staff-patient and visitor-patient care dyads. However, this development needs to be qualified in two respects. It must be noted that the construction of reciprocal relationships with people whose cognitive abilities are deteriorating, never to be regained, poses a considerable challenge to staff, and thus we observed few examples of genuine reciprocity between patients and staff. In addition, family members made only a marginal impact on the care settings which we studied. The difficulties which HCAs face in relating to family carers have been discussed in Section 5.

6.7 Conclusion: HCAs and relationship-centred care

HCAs provide most of the hands-on care in dementia wards and, as shown in Table 3, they made up at least 50 percent of all staff on the wards where this study was carried out. The evidence produced by the present study of HCAs therefore has implications for assessing the potential and actual implementation of health and workforce policy in relation to dementia care.

We found the development initiatives *Essence of Care* and *New Ways of Working* to have had a direct, positive impact on the individuals whom we studied and, while the *National Dementia Strategy* has limited practical applications for the HCA workforce in specialist settings, the values enshrined in this and other policy documents do set standards to which HCAs, as well as other formal carers, are invited to aspire. These values may be summed up in the concept of person-centred care.

When we examined our data in the light of person-centred care, we found that HCAs demonstrated the practice without much reference to its underlying principles. We also found that the strong emphasis on intra-staff relationships which we observed *in situ* is not reflected in the concept of person-centred care and we therefore conclude that 'relationship-focused care' is more applicable to the settings studied.

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7 Stress and coping: evidence from HCAs

Stress is a significant cause of sickness absence and underperformance in any workplace (64); therefore, addressing the causes of stress in the HCA role could benefit the whole workforce. Staffing levels were frequently cited as a source of stress by our interviewees. Even when shifts are not short-handed, as indicated throughout this report, dementia wards are stressful workplaces. In addition to the physically taxing labour and the emotional challenges of relating to this patient group, one of the most striking impressions gained from our participant observation concerns the violence and aggression on wards, which make staff anxious and sometimes fearful.

In these and other respects, stress is endemic to these wards and similar settings. This section seeks to highlight any issues which might be amenable to management interventions to reduce or manage stress and promote the wellbeing of health care staff in these settings. We draw on the management guidelines of the Health and Safety Executive (HSE), which have been widely used as a benchmark for assessing good management practice, to structure this discussion.

7.1 Stress management guidelines

The Health and Safety Executive's guidelines encapsulate evidence-based organisational standards of practice concerning work-related stress. They are grouped into six topics:

- Demands
- Control
- Support
- Relationships
- Role
- Change

Each standard is illustrated with a 'state to be achieved', which describes the 'organisational behaviour' recommended by the HSE. Our aim is not to audit such behaviour, since our access to the employing organisation was partial and limited to one set of staff in three wards over six months. Rather, the HSE management standards are used here as a tool to interrogate the data collected. They offer independent, objective, and for the most part verifiable indicators of good stress management. Below, we address each standard from the perspective of the study data. In doing so, we are looking at the generality of practice revealed by our observations. We are not aiming to highlight exceptions or breaches of good management practice, but to identify any areas where improvements may be indicated,

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subject to verification by others who are better informed about the organisation itself.

7.2 Achievable demands

Employees indicate that they are able to cope with the demands of their jobs; and systems are in place locally to respond to any individual concern.

'Demands' include issues such as workload, work patterns, and the work environment. The HSE prescribes what should be happening as follows: the organisation provides employees with adequate and achievable demands in relation to the agreed hours of work; people's skills and abilities are matched to the job demands; jobs are designed to be within the capabilities of employees; and employees' concerns about their work environment are addressed.

On each ward we studied, a minimum staff-to-patient ratio was required on every shift. On Ward A, five staff were required if there were less than 20 patients on the ward, with an extra staff member provided if the number of patients rose above 20. On Wards B and C, where patient numbers hovered consistently at 13, a minimum of four staff was required on every shift. On each ward, early shifts were provided with an extra member of staff to account for the greater demand of routine tasks.

It was not unusual on any of the wards for the staff quota to be met by asking staff who were not on the rota to come in, borrowing staff from other wards, or paying for agency staff. Even when the minimum level was met by the usual workforce, staff expressed a general sense of dissatisfaction with staffing quotas. Our observations suggest that low staffing levels and the stress generated by not being able to comfortably fulfil the demands of the work were a source of complaints on almost every shift, and this was confirmed through the interviews: when asked directly what they would like to see changed, staff consistently referred to staffing levels:

INT: What would you really like to change, if there's one thing that you could do about the ward?

RES: You know what's coming don't you! [laughing] I would like more staff, just more hands on. (H/CO, Ward C)

Many staff on Ward A were unhappy with the number of patients on the ward:

I think I'm speaking for most of the staff, we'd all feel better if we worked on a smaller unit. You know, have more staff to less patients so you could give them the attention they need. (H/HN, Ward A)

Participants felt that the standard staffing ratios failed to recognise the range and severity of patients' needs on dementia wards and in elderly care in general. Stress associated with insufficient staff was reinforced by the unpredictable nature of the environment and the fluctuations in routine demands, particularly around waking up, putting to bed, and mealtimes:

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Say you've got 19 patients but seven of those patients require hoisting and you've only got five staff on and each hoisting patient needs two to help them get up in the morning: you're going to be there until dinner time doing it… [A]t the minute, we've got like five 'feeders' and six staff so at dinner time it's just like mayhem. (H/PN, Ward A)

The challenge of appropriately staffing the peaks and troughs of daily routines was recognised by the ward managers, although they saw it as a difficult challenge to resolve:

I think sometimes when the ward is very busy they can really do with five until everybody is in bed, but you know nobody is going to come in and work three hours, nobody is going to stay on for three hours after their shift and I'm not paying five people to sit around for the rest of the night doing nothing, which is essentially what happens usually once they're all in bed, that is it. (QM/DZ, Ward A)

Staff acknowledged the difficulties faced by managers in providing enough staff on a finite budget. Yet, despite their empathy, staff remained generally critical about staffing decisions. Some staff suggested that the cost of providing more permanent staff would reduce the need for costly agency staff. Many also felt that low staffing levels illustrated the failure of 'management' to recognise the pressures of ward work:

In all fairness to the managers they've got to manage their budgets and stuff, but they don't realise that on the ward we've got to deal with the rubbish that's been dished out to us, in all fairness, we've got all the problems to solve. (Q/EK, Ward C)

This sense of injustice tended to reinforce the construction of group identities through the negative positioning of other wards. An example is the resentment felt when other wards borrowed staff to make up their numbers; this strategy was perceived by some to be inappropriate. Additionally, staff on Wards A and B felt burdened disproportionately by this demand, claiming that other wards did not always reciprocate:

We don't seem to get the support which we have offered to other wards. Other wards, they will just say, 'Right, we are struggling staffing-wise,' and we can't really do that. (Q/KR, Ward A)

Sometimes the [ward next door], they have four staff to six patients, and we have four staff to 13 patients. Sometimes our patients can be just as bad as their patients are, usually because they are classed as challenging behaviour. It's always our staff that have to go out to other wards, their staff don't. (H/ET, Ward B)

There were people who felt that team working could compensate for the lack of staff:

RES: I've been here a lot of years and as long as I can remember staffing has been a problem. But you come and you learn, you just learn to manage and deal with it. I mean we shouldn't, but we do manage, we've got to manage, you know.

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INT: Maybe that's why the importance of working together and things like that.

RES: Yes, pulling together, yes. (H/CO, Ward C)

For others, however, the constant pressure of perceived low staffing levels was felt to inhibit effective teamwork:

I'll tell you what, you know if we had the right amount of staff this ward would be awesome, because you wouldn't have that extra pressure on you. (Focus group, Ward C)

Two qualified nurses challenged the complaint about insufficient staff:

I always believe staffing is not about numbers, it's about well-motivated people who are willing to do their job at the best available opportunity… It's just a case of knowing our roles and how we achieve in working together as a team. (Q/KR, Ward A)

It's just staffing this, staffing that, staffing the other, they don't realise they've got to get used to working with the resources that they've got, they don't need more staffing, I'll be honest, they don't need more staffing, they've got to focus on managing their time effectively, and being smart. (QM/BU, Ward C)

Besides the absolute numbers of staff, the *mix* of staff on each shift was considered to impact the attainment of personalised care and patient choice (as promoted by the *Essence of Care*):

Certain patients don't like men or women doing them so we give them that, one of our patients doesn't like men doing her so we don't get the males to do her, you've got to give them a choice. (H/NE, Ward B)

With no male HCAs and only one part-time male nurse on one ward, it was certainly not always possible to fulfil patients' gender preferences, despite staff's best intentions.

As well as compromising the *Essence of Care*, low staffing was also perceived as reinforcing the risks of the HCA role:

I think there's always potential with a lower number of staff that you'll get an injury. (H/AI, Ward B)

RES: I think we take risks, I don't know, that's me, I think sometimes we take too much risk, especially when the staffing is low, and you have all these patients, well you never know what's going to happen, you never know. Sometimes it takes three nurses to one person, that leaves one nurse for...

INT: For 22 other people

RES: Yes… (Q/AN, Ward A)

It may be inferred that HCAs generally perceived staffing levels to be less than adequate, with adverse implications for patient care. Perhaps because of their position at the front lines of care provision, they felt that low staffing levels exposed both staff and patients to increased risks.

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7.3 Autonomy and control

Employees indicate that they are able to have a say about the way they do their work; and systems are in place locally to respond to any individual concerns.

'Control' in HSE terms is about how much say the person has in the way they do their work. This standard is likely to be met if: employees have control over their pace of work where possible; employees are encouraged to use their skills and initiative to do their work; where possible, employees are encouraged to develop new skills to help them undertake new and challenging pieces of work; the organisation encourages employees to develop their skills; employees have a say over when breaks can be taken; and employees are consulted over their work patterns.

Clearly, control over the pace of work is seriously compromised when there are staff shortages. The essential care given by HCAs cannot be pared down or postponed to 'pace' the job in most situations without detrimental effects on patients; they simply have to work longer and faster to compensate for staff absences.

While HCAs clearly exercised extensive informal control over their workplace, we observed that some of their ideas for innovation had not been taken up, even when change was planned:

The nurses and HCAs have some good ideas of what the ward really needs and become very animated and enthusiastic when discussing such ideas with one another. It is a shame, I feel, that staff were not able to have any input to the refurbishment as their expertise and extensive knowledge of the ward, routines, and patients would have been valuable to the appropriate and practical refurbishment of the ward. The refurbishment which the staff were soon to find out more about and to contest many of the plans and changes to be made, which they deemed inappropriate and a 'waste of money'. (Fieldnote, Ward C)

Any failure to engage HCAs in organisational planning will tend to reinforce their identity at the bottom of the ward 'pecking order' and their sense of embattlement vis-à-vis management and other staff groups, which can increase stress levels.

In practice, there was consultation over work patterns, to the extent that staff were empowered to adjust their own shifts to suit their needs. In addition, on Ward B, one of the responses to staffing pressures was to break staff up into groups and allocate sets of patients to each group, a good example of giving staff greater control over their work pace and pattern:

The group situation's better now … you're not so stressed as well, you know what you have to do, you do that patient for the rest of the day and that patient gets more quality time with you and you're not running around everywhere. (H/NE, Ward B)

Since we started the groups, I think it's better. We have two members of staff in charge of a group of patients and they are your responsibility

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throughout your shift. So, for the people that tend to be a bit more relaxed, they have to say 'Well, hang on a minute, I'm in charge of this group today so I have to buck my ideas up a bit'. (H/IN, Ward B)

7.3.1 Developing new skills

Given the evidence that dementia care skills are broadly lacking across the health and social care workforce, it is not surprising that training is an important policy priority, cited throughout the policy documents reviewed in Section 6. The resource implications of training were uppermost in participants' minds:

I think the training we have to do is relevant, but I suppose my biggest problem is we don't get enough, there's sometimes, you know, courses and away-days you want to go on and because of the staffing being at times quite poor on the ward that you don't get the opportunity to go, and sometimes you know I'd like to go, you don't always get the chance, even your mandatory training that you've got to do, and you get behind, manual handling and etcetera, because you can't be spared off the ward. (H/CO, Ward C)

Despite the recommendations of the All-Parliamentary Group that 'training and development programmes must also take into account the particular characteristics of the workforce' (22), courses were not always adapted to the variation in HCAs' educational preparation and learning styles:

When I returned there was a conversation going on between H/DY, H/AC, H/UA, and H/AI about the online lifting and handling training, which they said has now replaced the taught course. H/AI joked that she preferred the old course, because you got to skive for a day at [the training centre]. H/AC said she preferred the computer because she 'don't like sitting in a room being talked at'. H/DY said that she didn't think you learned as much from a computer because as long as she passed she always moved straight on, and was never inclined to go and check what she got wrong and improve. (Fieldnote, Ward B)

HCAs are expected to update their E-learning assessments regularly, which is encouraged on ward when time permits. E-learning was met with a general lack of enthusiasm, however, with few exceptions:

H/HA said that she couldn't access E-learning on the ward for some reason. N/WD and H/BA suggested she could do it at home. She laughed and told them she wouldn't do that, saying that work stays here and she's not taking it home with her. (Fieldnote, Ward C)

Continuing professional development is no less necessary for HCAS than other staff, not least because of the changing policy and legislative context within which they work. For example, the Mental Capacity Act 2005 (MCA) (65) was formulated to ensure that all decisions made on behalf of dementia sufferers, where they lack capacity, are in their best interests and take their wishes and desires into account (2). The following extract from a handover meeting illustrates the type of complex ethical decision which HCAs need ongoing training in order to address. The decision was taken by

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nurses in this case, but HCAs were also involved in dealing with the episode:

Q/JO went on to discuss [patient name] who had to be restrained in the morning when being dressed. Q/JO explained that [same patient name] was restrained because they had, after sometime struggling with [same patient name], managed to get her top half dressed, but [same patient name] was left naked on the bottom half. Q/JO said that if they had left her, [same patient name] would have walked about naked all day which 'obviously' she said, carried huge dignity issues, so they restrained her to dress her bottom half. Q/AG told her it would need to be documented, which Q/JO said she was halfway through. (Fieldnote, Ward C)

Knowledge of the Mental Capacity Act is clearly necessary for the consistent enactment of individualised care, but training HCAs on the Act is likely to require a carefully tailored approach.

We found evidence that lack of career progression discourages some staff from taking up training, while deterring others from even entering the workforce. Although training is given particular emphasis in dementia-related policies, there is very little mention of career development for nonqualified workers. One exception is the *Prepared to Care* report, which suggests that the Qualifications and Credit Framework (which reforms the National Vocational Qualification (NVQ) and Vocationally Related Qualifications (VRQ) system) may provide opportunities for career development among social care workers. Our interviews indicated that there is a good deal of uncertainty surrounding the value of NVQs, in light of the compulsory degree route toward nursing qualifications. Formerly, NVQs could help an ambitious HCA along this career path.

Would the prospect of promotion generate greater job satisfaction? The potential benefits need to be weighed up against the possibility that singling out individual HCAs for advancement could undermine team solidarity and identity as described in Section 4.

7.4 Information and support

Employees indicate that they receive adequate information and support from their colleagues and superiors; and systems are in place locally to respond to any individual concerns.

'Support' concerns the encouragement, sponsorship and resources provided by the organisation, line managers, and colleagues. This is an area where there were few serious complaints; the highly effective team seemed to provide a good deal of the necessary on-the-job support for HCAs:

Sometimes as well because there's so much stress, last year we were sort of having humour supervision, if that makes sense… We go in the office and we just, like, de-stress and then have a joke about it sort of thing. (Focus group, Ward C)

However, although informal support within the mutually respectful and affectionate team was valuable as a means to 'get it off your chest' or 'have

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it out', there were no mechanisms in place to guide, review, evaluate, and act upon the issues raised through this process. Consequently, there was limited opportunity to learn from such episodes and little apparent expectation of change or improvement.

The lack of professional supervision or formal counselling for job-related trauma or stress was a consistent theme in our findings. The main shortcomings noted in the support available to HCAs related to the fact that the organisation itself offered little support for the emotional impact of the work, in particular the physical abuse suffered:

Nobody can equip you emotionally to deal with that when you've been hurt, kicked or whatever, nobody, they don't have counselling you can go and get if you've had enough of it, there's nothing. (H/AI, Ward B)

Professional (clinical) supervision for the health care workforce was introduced in order to promote continuing professional development through reflective practice and shared experiences (66). The Department of Health defines professional supervision as 'a formal process of professional support and learning which enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice and enhance consumer protection and safety of care in complex clinical situations' (67). The DH also claims that provision of professional supervision has the potential to reduce poor practice and clarify lines of responsibility and accountability for client care (68). The *New Ways of Working* programme described in Section 6 recognises that nonqualified workers, such as HCAs, have often been excluded from supervision and proposes that suitable supervision and support should be in place for all staff, irrespective of seniority. At the time of the fieldwork, HCAs were not receiving individual supervision on any of the wards, though there were some forums for collective review and feedback.

Supervision can be delivered individually or in groups, and can cover a broad range of issues, from the strictly work-related to the personal. Not all types of supervision are designed to reflect this whole range; ward meetings, for example, are both staff- and patient-focused, whereas nurses' clinical supervision is often individualised and very personal. The following interview excerpt introduces one model of supervision, which is individually organised with someone outside the immediate ward, and explains some of the benefits:

RES: I think HCAs need more support in terms in clinical supervision, I think there are more issues than beyond just your job, if you wanted to go for clinical supervision which I don't think they have here.

INT: What would that involve?

RES: It's more personal discussions with somebody, like it could be an outsider.

INT: Like a mentor?

RES: Yeah, and you could say anything. (Q/ZR, Ward B)

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Ward managers characterised group supervision, usually undertaken in ward meetings, as a means to maintain care quality:

It tends to be… sometimes, probably twice a year we have a 'telling-off meeting' and we need to start pulling our socks up, it's little things that start to slip isn't it, like stocking up after one another, and making sure the backs are done, you know, things like that. But on the whole they're pretty good, and usually when we've had a meeting it perks up again. [laughing] (QM/SR, Ward A)

Managers had clearly struggled with the question of supervision and various models had been tried, but none seemed to be popular across the board:

It's always been about, supervision, but we're trying to literally embed it into practice now, and some people understand the benefits of it, some people don't, and some people, what's the saying, you can drag a horse to water but you can't make it drink. Well, we're going to have to start making it drink because, well everybody needs some kind of supervision… and it is supposed to be about work, so if people are saying 'Well, I don't get on with so and so', well that's not, it's not supposed to be a chat about your social life, or anything, it's supposed to be about work. But, if there is major conflict then obviously they will look at it as… you know. (QM/BU, Ward C)

Perhaps the biggest challenge facing individual supervision, however, was practical facilitation, given the stresses and constraints of the work. Like training, supervision can become a victim of inadequate staffing levels:

If I said to one of my lot at half past two 'are you going to stay for hour after your shift and have clinical supervision?', you'd see what they'd say: 'NO'. (QM/SR, Ward A)

I asked for a ward meeting before Christmas and they still haven't had one, something was bothering me at the time and I said we need a ward meeting… but we haven't had one, but now it's all gone and forgotten and I can't remember what that was for, that was five or six months ago. (H/AN, Ward A)

Although irregular, ward away-days and meetings were viewed favourably by most participants and we were told in interviews about practice improvements which had been developed through such opportunities.

7.5 Relationships

Employees indicate that they are not subjected to unacceptable behaviours, e.g. bullying at work; and systems are in place locally to respond to any individual concerns.

Offsetting stress through relationships involves: the promotion of positive working in order to avoid conflict and ensure fairness; employees sharing information relevant to their work; the development of policies and procedures to prevent or resolve unacceptable behaviour; systems put in place to enable and encourage managers to deal with unacceptable

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behaviour; and systems put in place to enable and encourage employees to report unacceptable behaviour.

Within the context of an NHS Trust with established policies on equality and diversity, we observed that codes of conduct were relatively well-developed, monitored by management, and for the most part reinforced by peer pressure within the staff team. When this failed, some interviewees saw ward meetings as an opportunity to address unacceptable behaviour at work:

I'm not very good at confronting people, I just blurt it all out and it all comes out wrong, but I think myself, the ward meetings you should be able to get it out in a ward meeting, and then you can say in the ward meeting what is bothering you, and you can say things like, 'Look, I'm going in a room and things are a mess every time I go in there, I'm clearing up after other staff that have left bowls out and not wiped the bowls or not done this or not done'… I know that sounds silly but it is all part of the job, you can say that in ward meetings you see. (H/AN, Ward A)

7.6 Role

Employees indicate that they understand their role and responsibilities; and systems are in place locally to respond to any individual concerns.

Stress can be avoided if people understand their role within the organisation and the organisation ensures that the person does not have conflicting roles. To make this so, the organisation must ensure that, as far as possible: the different requirements it places upon employees are compatible; employees are provided with sufficient information to understand their role and responsibilities; the requirements placed upon employees are clear; and systems are in place to enable employees to raise concerns about any uncertainties or conflicts they have in their role and responsibilities.

There was considerable variation in the tasks undertaken by HCAs across the three wards studied. The general hospital assessment ward involved HCAs most in medication and nursing tasks, like taking blood pressure, while the other two sites reserved such clinical tasks for qualified nurses. Within each site, however, there seemed to be adequate role clarity. The close interaction between HCAs and the qualified nurses responsible for managing the ward meant that any role-related problems could be quickly resolved.

Our observations suggest that although HCAs enjoy considerable role clarity, their formal job description does not encompass their entire role. We found that they played a major part in managing the environment on the wards, using their emotional labour and behavioural tactics to promote the wellbeing of patients and staff. Although this role was not generally acknowledged, neither was it the domain of any other health care workers, so HCAs were not challenged in carrying it out.

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However, since their expertise is regarded as non-clinical, HCAs were seldom consulted about medical matters:

Another topic of conversation around the table was of the fact that HCAs are not allowed to have a say in some patient matters, for example if a doctor asks for information, a staff nurse must be consulted, and also that HCAs cannot check blood pressure and other related tasks. N/EK voiced her opinion that the HCAs are often the most knowledgeable about the patients and the job, especially, referring to H/GL, that people who have been HCAs for years ('19 years', H/GL interrupted), should be praised for their work, and should be allowed to have more clinical input and more training. (Fieldnote, Ward C)

This reflects on the limited role of HCAs as members of the multidisciplinary team, particularly given the fact that they were mostly not included in ward rounds, a standard forum for sharing knowledge about patients. As a consequence, HCAs' knowledge was not systematically shared with the other staff, unless the latter asked for it expressly. This issue relates not only to the scope and clarity of their role but also to their level of empowerment in the job.

7.7 Change

Employees indicate that the organisation engages them frequently when undergoing an organisational change; and systems are in place locally to respond to any individual concerns.

The management and communication of organisational change (large or small) can be a source of stress. In order to meet the HSE 'change' standard, the organisation provides employees with timely information to enable them to understand the reasons for proposed changes; ensures adequate employee consultation on changes; and provides opportunities for employees to influence proposals.

The general sense of disempowerment felt by HCAs extended to their feelings about organisational change:

You feel that whatever you do, you necessarily can't change things… You're not necessarily equipped with the authority to make an impact. (H/BN, Ward A)

Communication about change is difficult throughout any organisation, particularly in one as large and complex (with several thousand employees) as the NHS Trust within which we conducted this study. The HCAs working on the three dementia care wards did not generally feel that they were informed adequately about changes:

RES: I don't know if the Trust knows what they're doing, for one minute they say we're moving from here, they're going to do this, and then the next minute it's going to be another five years, I don't know what's going on, I don't know what's going on. So they start blocking off outside on that side, seen the block over by the windows and I thought, oh, for they want to build a children's unit or something like that, but I don't know what's

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going off, honestly, you just hear rumours, you don't know what's happening, because I mean they said the men's side, keep that for the young onset and block it off, but next minute they change their mind, so I don't know what's going on. I don't know what's going on.

INT: You just kind of wait and see.

RES: Just wait and see what's going to happen. (Q/AN, Ward A)

Nonetheless, staff appeared to be reconciled to this general sense of uncertainty and lack of knowledge about change in the organisation. Citing many examples of developments affecting their work over which they felt they had no say, they did not express high expectations of being kept informed in future.

7.8 Conclusion: areas for management of stress

The HCAs were not passive victims of the manifold sources of stress affecting them personally, their role, and the setting within which they work. They recognise the impact of stress and appeared, both individually and as a team, to have developed sophisticated strategies for minimising it, as discussed in Sections 4 and 5. All their efforts to manage the environment on the ward are directed at improving conditions for staff as well as patients. They rely on 'the team' to ensure a fair distribution of the workload and to provide a strong network of emotional support and risk management. Left to their own devices, HCAs demonstrated ingenuity in dealing with stress at work.

However, this section raises a few points for consideration at the organisational or management level which, if addressed effectively, could enhance the HCAs' job satisfaction, increase their sense of pride and autonomy, and reduce work-related stress. In particular, the pressure points seemed to be:

- Perceived low staffing levels
- Training and professional support
- Recognition and knowledge transfer
- Communication about change

These themes will emerge in our recommendations as aspects which employing organisations might consider reviewing in relation to HCAs, in order to improve the recognition and retention of these key skilled workers. In the following section, we probe more deeply into the thorny issues of recognition and involvement.

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8 Staff recognition and involvement

Turnover rates among HCAs on two of the three inpatient dementia wards included in this study were considerably lower than average for inpatient services in the Trust in which they were located during 2008-09 (3.4% and 2.8% compared to an average of 7.7%). In the third they were higher (9.7%). Our data suggest that, where it applies, staff longevity is promoted by stable management and relatively good job conditions, as evidenced against HSE standards in Section 7, including flexible shift patterns, adequate annual leave, satisfactory wages with the possibility of overtime, and supportive line management.

Nonetheless, some participants reported feeling under-recognised and undervalued. As one nurse reported:

I've been an HCA, I know you just get swept under the carpet. (N/WD, Ward C)

Drawing on the study data, the following section will explore how support, recognition, and reward for HCAs may provide an avenue to improved dementia care. This avenue has been rarely explored in policy documents to date, with the exception of the *Prepared to Care* report (22) which advocated that 'workforce development programmes must be carefully designed to meet the needs of care staff and ultimately improve lives of people with dementia'.

8.1 Appreciation and pay

Discussion about the situation of HCAs should be contextualised within the broader devaluation of mental health services for older people, described in conversations and interviews as the 'poor relation' of the health service. This notion is supported by recent cross-national research, which found that the devaluation of nursing assistants in dementia care was directly related to the broader institutional devaluation of older people (69).

HCAs frequently reported feeling under-valued by other more senior members of the multidisciplinary team. Within this, doctors were a frequent source of complaint, with HCAs commenting that they were often patronised or simply ignored by doctors. In group situations, HCAs would frequently make light of this issue through humorous critiques of the assumed 'expertise' of doctors:

H/PL described the doctor's implied incompetence ('some of these doctors are scared of the patients here, I think') – [patient name] was holding onto her arm, lashing out at her with the other hand, and H/PL was trying to defend herself while also reaching for the alarm button – and 'he was just sitting there, reading a book!' she said as she re-enacted her movements. (Fieldnote, Ward A)

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The low status of HCAs is consistent with their low remuneration compared to others on the ward, as discussed by HCAs in the following fieldnote:

They then spoke about pay bands, H/RA telling N/WD that it was unfair that [two environmental co-ordinators] were paid at a higher band level than that of the HCAs… [yet] they both work better, more sociable hours, and do less physical work. (Fieldnote, Ward C)

In contrast to such overt discussions on Ward C, pay issues were rarely raised on the other two wards. One researcher reflected that this might be due to 'silent solidarity' (Fieldnote, Ward B), since all the HCAs receive equally low pay. It should be noted that one HCA reported satisfaction with her paycheck, nevertheless:

RES: I think we get paid quite well actually.

INT: Do you?

RES: Yeah, compared to people that work in supermarkets I think we get paid really well.

INT: Do you think the job is comparable to stacking shelves in a supermarket?

RES: Well, no, I think it's a bit harder, but I think we get paid well, people moan that the wages aren't very good, I think the wages are liveable. (H/ET, Ward B)

While this favourable comparison conveys satisfaction with pay, the selection of a supermarket worker as comparator indicates the HCA's perceived self-status. As highlighted in the following focus-group excerpt, low self-esteem may be exacerbated by the lack of formal mechanisms (beyond remuneration) for recognising the HCAs' daily contribution:

N/EK: Like I said they're the eyes for us trained staff, you know, when you're just busy running round, they're the eyes.

N/WD: Making out we know what we're doing!

N/EK: And it's just like, yes you should get more recognition I feel, you guys should.

INT: Do you feel you'd benefit from more recognition?

H/LA: Well, it'd be nice.

N/EK: You'd feel a bit more valued isn't it, as a team member. And you'd sort of be more, uh, happier to be involved in certain roles on the ward.

H/LA: Well it would be nice if you were included in, instead of, 'Oh, that's just the HCA'. (Focus group, Ward C)

The relationship between HCAs and qualified nurses can be both a source of recognition and a source of devaluation. Some staff nurses explicitly acknowledged that the HCAs are the 'eyes' of the ward. Nevertheless, HCAs reported feeling devalued by the fact that they undertook many of the same jobs as nurses, but with significantly less reward:

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RES: It's a waste of time speaking about it, because we're just here to do the job, and they've done three years' training and they're more important than us.

INT: It's quite unfair because you're all giving the same care to the patients, you're on the front line.

RES: They'll throw it in your face, they've done three years' training. I mean you must have noticed it when you was on here, that you was left out on the shop floor on your own quite a lot. (H/GL, Ward C)

Both nurses and HCAs agreed that there was a lack of recognition of HCAs on the part of higher levels of management:

INT: What should a good manager do? What do you feel they should do?

RES: They should come on the floor more, see what we do, I know they have a lot of paperwork to do but there's more than paperwork to do. It would be nice if they knew the patients were by name not just by faces, and also knew the staff names, simple! (H/NE, Ward B)

I mean I think it would be nice if it was only twice a year or something, to come round and say to the staff: 'How are you? How you getting on? Are you alright?' But it don't happen. I mean they do the staff partnership days, but then you get staff who don't like going and they don't want to go, and you know things like that, but they don't actually come to the ward and say 'How are you?' Only if you've got posh visitors coming round, then you might see them. (Q/SR, Ward A)

Interview responses from nurses and HCAs suggest that this problem might be redressed, at least symbolically, if managers were to visit the wards more often and address the front-line staff as equal and valued workers.

8.2 Input in decision-making

The extent to which HCAs feel they are able to influence care planning and ward management is one indicator of how far they feel valued and respected.:

You discuss it with the staff nurses and you relay your views, it filters through to ward managerial staff, but … you just think, you know, you're not really listening to what I'm trying to say, you know, and you listen to people in the team and they're all kind of sharing very similar views and you're thinking, well, why is it we're all feeling the same and yet we're in the same situation, no change has been made? That is a very demoralising aspect, when you feel that there's part of the care that you just can't change, you know? (H/BN, Ward A)

Hardest thing? [long pause] I don't think there's … I suppose you get, I think personal frustration that nothing gets done. It's not physically hard, it's not mentally hard I don't think, you're just frustrated that things don't get done, that's the hardest part of the job, I think anyway. (H/GL, Ward C)

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This sense of impotence in the face of organisational inertia was not restricted to HCAs, as highlighted by this comment from a qualified nurse:

Me and one of the HCAs, we did a timetable for more activities, I know it's really difficult to do activities on the ward but I think we need to do more with the patients, so me and the HCA tried to do the timetable but it got pushed aside and not required – and I think sometimes you feel you're fighting a losing battle. (Q/BE, Ward B)

While the majority of interview comments supported the view that HCAs were not engaged in decision-making processes, some respondents suggested that HCAs *were* consulted on certain matters, especially on Ward B:

Both H/ET and H/DY were complimenting Ward B for the way in which the staff were able to work together. They felt like their opinions about patients were included in decision-making, which seemed important to both. (Fieldnote, Ward B)

In general, both HCAs and qualified nurses seemed keen to promote more opportunities for dialogue. Handover meetings offer particular potential for increasing input in care planning from HCAs on all three wards. In practice, we noted that the level of HCA input was minimal, with variation due to the personnel involved, the time of day and other circumstantial factors such as the nature of the previous shift. As an exception to the general rule, the following example suggests how HCAs could participate more meaningfully in handover:

Today's handover seemed very long, but when we finished it was only 2.10. I think it seemed long because it was full of discussion rather than simply a short description of behaviours, medication and dietary intake. Of course it still included these but was surrounded by a full discussion by both Q/JO, N/WD and also H/ND who was working a long day and who Q/JO invited to inform the group of how some patients had been when she had got them up and dressed this morning. I have never seen HCAs welcomed into the nurses' handover discussion before… It gave a much fuller account of patients before they were up and dressed and under nurses' supervision in the dayroom. I felt it also recognised the HCAs' work as significant and allowed this to come from an HCA perspective rather than being reported more generally by a nurse who isn't always there. It is the team that works together to keep the ward running smoothly, so should it not be the team that hands over rather than just the charge nurse? (Fieldnote, Ward C)

It was clear that HCAs *did* provide input behind-the-scenes, for example by writing in the notes (especially on Ward C) or talking informally to nurses (on all three wards). As our fieldwork concluded, Ward B was developing a forum for discussing individual patients' care in which, at least in principle, HCAs would be equal participants. However, after the first few meetings, the ward psychologist who was running the meetings reported disappointing results, including a '*lack of enthusiasm, pessimism and negative vibe'* (Fieldnote, Ward B). However:

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Q/BE expressed surprise at this as she said she had always got plenty out of them – and further that it was a bit of a fight to even get into them because people were keen to attend and someone had to stay and watch the ward. (Fieldnote, Ward B)

This difference in perspectives about the patient-care forum was echoed in our interviews with staff, with most HCAs stating their support in principle and practice while the deputy manager reported 'herding' people to enforce attendance.

The need to accommodate shift patterns is an important consideration in organising events such as the patient-care meetings. As a research team, we encountered this issue when scheduling feedback sessions for the staff, particularly because we failed to anticipate that some HCAs would simply be too tired to attend an hour's meeting if it came at the end of their shift.

Nonetheless, HCAs constantly generated ideas about how to improve patient care and the ward environment, as noted throughout our observations and interviews. Their ideas, which were based on their detailed shop-floor knowledge, ranged from small environmental changes to the restructuring of patient activities and everything in between:

So what we need is, ideally, is a cupboard in the toilets that you can access the bits and bobs from. In these toilets, you need everything there. (H/BN, Ward A)

And I tell you another thing what I'd like… When I was working with the challenging behaviour we used to take them out, we used to have trips out, we'd get on a minibus and we'd go somewhere, out for lunch, we'd have pub lunch, or we'd go to a garden centre or something, and it was just nice. I mean when you get the patients off the ward environment you see, you know they behave differently, and react differently, and that is just so nice and so rewarding, and I have missed that on here because we don't really get a chance to take them off. (H/CO, Ward C)

If I were to build a purpose-built unit it would be fantastic, because I think I'd have a big circle round a dayroom, or something, just so that the patients could just walk round in a big circle… Just have a big area that they can just walk round, but you could visualise them as well, would be great, and because the walking round, the de-stressing… I think there's a long way to go in dementia care, I think there's a lot of things they can tweak. (H/BN, Ward A)

8.3 Conclusion: development needs

Although we did not set out to study recognition, pay, and other organisational aspects of the HCA job, this theme emerged from the subjective experience of the staff we observed and interviewed. Putting aside the prospect of pay increases in the present context of economic stringency, the evidence summarised here suggests that management could build on the satisfaction and enthusiasm generated among HCAs when their views were taken into account. Complaints about pay and conditions were

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not part of everyday conversation on the ward, but a sense of being devalued members of the hierarchy was certainly prevalent.

An approach which successfully involves HCAs in decision-making and in bringing about improvements in the care process, such as the approaches offered by *Essence of Care* and *New Ways of Working* (discussed in Section 6), might overcome some of this perceived marginalisation. At relatively little cost, such an approach would potentially improve the HCAs' job satisfaction, boost morale, and benefit the quality of patient care.

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9 Conclusion and recommendations

The research team met with staff at the end of the study to give them an opportunity to consider our preliminary findings and provide crucial feedback on the inferences drawn. In that forum, the researchers who had completed the participant observations paid tribute to their colleagues through individual reflections on the research experience. Those reflections are reproduced here to link the inferences that we are making in this section back to their source, and to remind us that they should be read as the tentative suggestions of observers whose viewpoints are unavoidably limited by a range of factors.

9.1 Researchers' reflections

Ward A Researcher: *As most of you know, I arrived for my first shift with no direct health care experience and limited first-hand understanding of acute dementia. I remember standing in front of the ward door, taking a deep breath, and reaching out to press the buzzer, with no idea what to expect when the door opened.*

And yes, the first couple of shifts were as hard as I imagined they would be. To an outsider, stepping onto the ward is like stepping into a different world. The distinctive smells, all the different sounds, the hum of activities, the unfamiliar patients – it's overwhelming. And I was daunted by the many and varied tasks performed by the HCAs. Though, with confidence and years of experience, you complete them without thinking twice, I had to learn them from scratch – and some of those tasks are not as easy as you make them look.

But fortunately, I was quickly welcomed into the team and shown, step-by-step, shift-by-shift, how to be an HCA – from folding hospital corners to performing intimate bodily care, from calming a distressed patient to staying safe to keeping a sense of humour, no matter what… And as I learned from you, my confidence grew, and so did my enjoyment in the role – so that I began to experience some of the rewards of the role that you mentioned in your interviews. Rewards that come from connecting positively with patients, working together well as team, helping visitors navigate the ward, and so on.

Of course there were difficult shifts along the way, when the patients seemed particularly loud or restless, when the mood among staff was low, when I was feeling tired and impatient. But overall, I looked forward to coming into work and I learned so much every single shift. I remain deeply respectful of the work you do and appreciative of your willingness to share with me some of your skills, experience, and reflections on that work.

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Ward B Researcher*: There were many things that gave me a sense of apprehension before starting my time on ward. My lack of knowledge*

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about dementia, what dementia patients looked like, did, sounded like and what it would take to provide them with care. My experience of training did little to dispel this. Due to an admin error, the first day's training I received was the second of the two-day violence and aggression course, the week before I was due to start on ward, where I found myself learning how to grab, pull, push, lever and throw, all the time wondering just exactly what I had got myself into.

I remember my first shift very clearly because many of my concerns were almost immediately relieved, not only by the very friendly introductions I received, but by the sense in which I felt that here was a relaxed, happy, close, teasing, caring group of people, and the immediate sense of security this provided me with gave me confidence that I could face whatever challenges the job may throw at me.

I gained a great deal of fulfilment from my time on ward and it was an experience which touched me very deeply. Caring for patients, from waking up, to feeding, to putting to bed was a source of consistent satisfaction – funny to me how often the patients who provided the biggest challenge were the ones who would become favourites.

Despite this fulfilment, I found the work to be extremely tough. After my first three months on ward I was physically exhausted, my back and shoulders used to ache, my sleep patterns were all over the place. After my weekend of nights the world seemed a disorienting, semi-conscious place and after my two long days working Christmas Eve and Christmas Day I felt like I had gained some insight into a world of physical, relational and emotional demand that I do not think I could deal with on a permanent basis. What kept me going was the nurture, support, and friendship of the people I worked with. I feel very privileged to have shared in some of this and would like to thank everyone – staff and patients – who made this experience such a fulfilling and heart-warming one.

***

Ward C Researcher: *When I walked onto the ward for my first shift, my heart was racing, my stomach was churning and I had no idea what I'd let myself in for. After muffling my way through an introduction, someone told me: 'Come and sit down, duck, while we do handover'. Not long after this, I was shown around the ward and soon felt welcomed as a fellow HCA. The first few shifts were pretty hard-going, seeing as I had little experience with the work or with people with dementia. Everything seemed to come naturally to you all whilst I found myself fumbling around with tasks, trying to talk to and get to know the patients – and generally getting in the way.*

However, after only two or three shifts, my nerves about coming to the ward disappeared. I began to look forward to my shifts and to working with you all. I saw how well the team all work together and get along so well, having fun and laughs throughout even the most stressful of times. There were times when shifts were difficult, noisy and tiring; and on these shifts I was able to really experience the challenges of the job that you all work through together and cope with, week in, week out. However, the majority

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of the time, the atmosphere on the ward is kept so positive that it outweighs any stresses on shift. I learned a huge amount from working with you all and enjoyed my time here so much that I still find myself missing it now! I am so thankful for your willingness to share your work life with me and I truly respect the work you all do. Thanks for making me feel part of the team, for teaching me so much, and for giving your time to the project.

9.2 Research questions revisited

The research reported here tackles a number of questions about working in dementia care from the perspective of an HCA. The knowledge gained from our observations, interviews, and insights into the individual experience of working as an HCA extends far beyond the original research questions, but we return to them here as a framework for summarising what we have discovered. The study set out to answer the following questions:

- 1. What motivates staff?
- 2. What obstacles to good care do they face?
- 3. What do they find stressful and how do they cope?
- 4. What appears to promote staff wellbeing?
- 5. What differences exist between different groups of staff (older-younger, male-female, ethnic majority-minority)?
- 6. What are the implications of these findings for person-centred care, which is set as a standard of good practice?

Question five proved impossible to answer because our sample lacked the necessary diversity, and question six we shall leave till last. We will examine the first four questions according to two major themes explored in this report: first, the *process* of caring in terms of its motivations and rewards for HCAs; and second, the *impact* of caring, discussed here in terms of stress and its management.

9.3 Caring, motivations and rewards

We have described what HCAs do in principle and in practice in Section 3. We found that a number of HCAs exceed their basic job role by taking on additional tasks to the benefit of both the patients and the staff team. With variation across the three wards, those extra duties included: dressing wounds, assisting with medications, cleaning, food preparation, and more. For the most part, we found that the HCA role is undertaken with warmth, empathy, and commitment, and it is clear that most HCAs derive great satisfaction and reward from caring for people who are largely dependent and powerless. Many told us that their greatest satisfaction comes from improving patients' quality of life in small ways. While the caring role has always been central to nurses' understanding of their work, as well as

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patients' expectations of that work, we have ample evidence that this is equally true for HCAs, even though it may not be widely recognised.

9.3.1 Managing the emotional climate

We found that HCAs do more than care for individual patients: they also manage the emotional climate on the ward, stimulating the environment when it has become dull and calming things down when stress levels rise. The importance of this function in the overall care of people with dementia may be underestimated, and HCAs' particular capability in this respect has not to our knowledge been recognised in previous research. We argue in Section 5 that this is a distinctive and important aspect of the HCA role.

9.3.2 Working with families

Communication with patients' families emerged as an area which might benefit from further attention. The hospitalisation of a person with dementia can be a very stressful and distressing event for friends and family members. When they visit the ward, these 'informal carers' may bring with them a whole range of emotions, most of them negative, including guilt, fear, bewilderment, sadness, disempowerment, and anger. Although the qualified nursing staff communicate with them on clinical matters related to diagnosis and treatment, the HCAs provide a valuable, direct link to the patients. It is the HCAs who can update relatives on minute daily details about their loved one.

We observed that the relationship between HCAs and visitors is often guarded and sometimes strained, perhaps because of the potential for misunderstanding and negative interactions. Equally, when we talked separately to informal carers, they told us that it can be difficult to know how to approach HCAs and ask questions or provide suggestions without seeming critical and encountering defensive responses. Our analysis was validated by the Project Advisory group and ward staff: the interface between HCAs and visitors to the ward is an aspect which deserves greater input from management and research.

9.4 Stress and coping

The analysis of stress and coping in Sections 3 and 4 is largely descriptive, drawing out the themes about which we gathered data, in keeping with an unstructured, qualitative approach. Section 7 departs from this methodology to undertake a structured analysis of our data in relation to the HSE stress management standards. The use of these two approaches to data analysis gives added strength to the points about which they agree.

9.4.1 Positive and negative functions of the team

Through our qualitative data analysis, we were repeatedly led to the conclusion that belonging to and participating in the team is a fundamental part of the HCA role. The pervasive impact of the team is reflected in its reappearance throughout this report. We identified three positive functions

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of teamwork. First, the team was found to help sustain and support its members, countering many stressful aspects of the job. The ability of staff to co-operate well in complex and changing situations was largely due to this high level of mutual understanding and trust. Second, the team is built on a foundation of mutual respect and appreciation. This encourages everyone to fulfil their role with confidence despite receiving limited recognition or appreciation from others, including patients, higher management, and the wider world. Thus, the team is a source of identity, pride, and self-esteem. Third, team members rely on each other for emotional support to permit them to deal with the presence of incurable disease, loss of dignity, and death among the people for whom they care. HCAs look out for each other, monitoring levels of personal stress on and off the job. They also actively displace negative emotions through humour and detachment tactics.

However, we did observe two potential risks posed by the closeness of the staff team. First, we noticed that, although the HCAs maintained a careful balance between staff and patient needs most of the time, at times the balance shifted. In such moments, staff appeared to focus more on meeting the needs of the team or on efficiently completing tasks such as toileting or feeding, to the detriment of providing a high standard of individualised care to each patient. Task efficiency sometimes became the priority during particularly busy periods on the ward, such as mealtimes; whereas during slower periods, the social experience of the staff sometimes appeared more of a priority than the social stimulation of the patients.

A second, potentially negative result of close-knit teams is that they can discourage communication with others outside the team. There seemed to be relatively few opportunities for HCAs to share their knowledge about individual patients with the rest of the multidisciplinary team, while the security provided by the team may also cut HCAs off from interacting with patient's families or with professionals from outside the ward. This may be related to a lack of appreciation of HCAs' knowledge on the part of other staff and the 'us and them' mentality between the HCAs and the wider group of care providers.

While team building and team identity are evidently a positive experience for HCAs, it may also be possible to raise the status of the HCA team in the eyes of other staff, for instance through training and rewards, and to involve its members more in ward rounds, and carers' groups. This could increase the HCAs' awareness of their role *vis a vis* other systems, and make them less inclined to be inward looking.

9.4.2 Humour and desensitisation

We found that HCAs deployed tactics which enabled them to function consistently in a role which demands a high level of emotional as well as physical energy. They have a wide repertoire of skills for communicating with severely impaired patients, and derive satisfaction from small signs of progress. Their levels of empathic engagement vary according to other contextual factors, and HCAs are experts in rationing their emotional labour

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to last to the end of each shift. Their work can be made more difficult by insufficient staff, unpredictable patient behaviour, and lack of recognition and involvement in care planning.

HCAs invariably use humour in their work, and sometimes cope with the most stressful situations by detaching themselves emotionally. The ability to assume indifference to unpleasant tasks and personal abuse, which we call desensitisation, is an essential requirement to function successfully as an HCA.

9.4.3 Performance against HSE benchmarks

By comparison with the HSE standards, we found that perceived low staffing levels, limited training and career development opportunities, lack of recognition and appreciation of the HCAs' knowledge concerning individual patients, and poor communication about change were key organisational issues in relation to stress management. However, the management context with regard to autonomy, roles, and support could be judged as largely satisfactory, with relationships being very well managed. Again, the team was a powerful normative influence in this regard.

Many HCAs were entirely satisfied with their current job content, but others were keen to engage in further training and develop new skills. In identifying aspects of the job which could be developed further or made more central to the HCA remit, we are not suggesting that HCAs should adopt new roles and responsibilities without an equivalent increase in recompense.

9.5 Implications for person-centred care

The concept of person-centred care is largely implicit, rather than explicit, in the work of the HCAs. As we argue in Section 6, person-centred care may not be the most applicable model; rather, relationship-centred care offers a more comprehensive understanding of the care dynamic which underpins practice in dementia care. Further work may be needed to develop a suitable theoretical framework incorporating relationship-centred care and to test its impact on patient outcomes.

9.6 Questions for consideration and implications for the NHS

The findings of our study lead us to suggest that it is time to re-evaluate the practice of HCAs in hospital dementia settings as professionals with key functions in the delivery of care to people with severe dementia. Several questions arise to guide this re-evaluation in relation to the following nine dimensions of the HCA workforce:

- **Staffing levels**. Are there further measures which might reduce absences through stress or work-related injuries which lead to staff shortages, increase the staff time available for hands-on care, or reduce the housekeeping workload on HCAs, enabling them to spend

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more time with patients? Initiatives to streamline activities which do not involve patients, such as 'the productive ward' have much to offer in environments like those studied.

- **Training**. Do we know enough about HCAs' training needs? What are the most appropriate means to address these? Not all HCAs had received formal dementia awareness training, while their responses to internet-based training courses were unenthusiastic, with few exceptions. It appears (at least in the study context) that most training opportunities are targeted at qualified staff, to meet continuing professional development requirements, and that HCAs might benefit from appropriate training opportunities.
- **Professional support**. What are HCAs' specific needs and preferred approaches to professional support or 'clinical' supervision? This is an area where ward managers felt that various models had been tried and found inadequate. Options include: individual or group supervision, peer-led or led by a manager outside the ward, from an analytic or task-focussed perspective.
- **Team working**. Do existing systems of recruitment, career development and appraisal reflect the importance of team working in the effective delivery of dementia care? How can team working be supported and enhanced without engendering 'isolationist tendencies' on the part of the team?
- **Recognition**. Does the actual role of the HCA correspond to expectations? We found that important aspects of HCAs' functions were not widely recognised. Raising awareness of the role among the general public, promoting its importance to relatives and colleagues and formally acknowledging this workforce's contribution through performance-related awards might offer some mechanisms to increase its status.
- **Roles**. Our HCAs certainly felt that they knew the patients in dementia wards better than any other professional group, and this was endorsed by some nurses interviewed. Relatives may see this, yet their enquiries tend to be referred to qualified nurses by HCAs who are wary of 'saying the wrong thing' to visitors to the ward. How can the knowledge held by HCAs best be shared with informal carers and how can carers best help to inform the work of HCAs? Is liaising with families a role which could be developed to enhance the job of some HCAs?
- **Rewards**. Is the job adequately described in *Agenda for Change*? Are all the capabilities and skills which HCAs deploy reflected there? Should undertaking clinical tasks, dealing with antisocial behaviour, or other roles attract enhancements? Most staff appear to be employed on Band 3, but there was a suggestion that Band 4 is 'underused' and could be a suitable level for experienced HCAs who undertook additional training or responsibilities, such as supervision or training of other HCAs. It should be noted that it is a widely-held

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belief that clinical tasks which were once undertaken by qualified nurses have been devolved to HCAs. We found some evidence of clinical involvement (3.11) but we have no baseline against which to compare the status quo.

- **Knowledge transfer**. How can systems of ward communication be adapted to value and integrate the knowledge held by HCAs into the caring process? Should they be included routinely in ward rounds? Should they contribute to patients' notes? Are there other approaches to knowledge transfer which are better suited to HCAs?
- **Communication about change**. Are existing channels of communication in the organisation adequate to reach HCAs, bearing in mind that computers are not used by all staff? What information is most needed by HCAs and other staff who are principally engaged in patient care activities?

9.7 Implications for the NHS

We observed HCAs working with highly vulnerable and dependent people who made extraordinary emotional and physical demands of them. The observations and analyses presented in this report are intended to describe the breadth and depth of the HCA role in this context and to explain some factors that appear to influence job performance. The areas for development highlighted here can reasonably be expected to have a positive impact on the quality of dementia care, not only in specialist MHSOP settings, but also in acute hospitals, which are being encouraged by the *National Dementia Strategy* to meet the needs of increasing numbers of patients who have dementia.

The NHS Constitution (77) includes 'pledges' to staff on the part of employers and concomitant staff 'duties'. The employers' pledges are relevant to our findings. 'The pledges are made by all employers that provide NHS services, and are made to all staff that deliver NHS care, both professional and non-professional. The pledges are not legally binding but represent a commitment by the NHS to provide high-quality working environments for staff.' (78, p93). The following text is taken from the revised NHS Constitution.

'Staff pledges

The pledges to NHS staff reaffirm the vision that quality workplaces should exist for all staff delivering NHS services - they should not just be the preserve of high-performing organisations. This is important, since the evidence suggests that there is a clear connection between the experiences of patients and staff.

The pledges are made by all employers that provide NHS services, and are made to all staff that deliver NHS care, both professional and non-professional.

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The pledges are not legally binding but represent a commitment by the NHS to provide high-quality working environments for staff.

1. The NHS commits to provide all staff with clear roles and responsibilities and rewarding jobs for teams and individuals that make a difference to patients, their families and carers and communities

2. The NHS commits to provide all staff with personal development, access to appropriate training for their jobs and line management support to succeed

3. The NHS commits to provide support and opportunities for staff to maintain their health, well-being and safety

4. The NHS commits to engage staff in decisions that affect them and the services they provide, individually, through representative organisations and through local partnership working arrangements. All staff will be empowered to put forward ways to deliver better and safer services for patients and their families.' (77, p10)

In the Handbook to the NHS Constitution (78) each of these pledges is unpacked in terms of what it means in practice. Some work is under way, some is projected. The present study implies that the implementation of the NHS Constitution will not be complete without giving full attention to the work done by HCAs, by addressing the questions raised by this study.

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References

1. National Statistics. The Mental Health of Older People 2003.

2. Department of Heal th. Li ving well wi th dementi a: A nati onal dementia strategy. London: DOH2009.

3. Department of Heal th. The Nati onal Service Framework for Older People. London2001.

4. Balance of C are Group. Identifying al ternatives t o h ospital f or pe ople w ith dementia: Lincolnshire Primary Care Trust2007 March 2007.

5. Suhonen R, Val imaki M, L eino-Kilpic H. "Individualised care" f rom patients', nurses' and relatives' perspective—a review of the literature. International Journal of Nursing Studies 2002;39 645-54

6. Kontos P, Poland B, Mitchell G, Cott C, M cGilton K. Caring as an act of resistance: Moral agency on the front lines of dementia care. Journal of Nutrition, Health and Aging2009;13(S1):S144

7. Department of Heal th. Movi ng on : Key l essons from Rowan Ward: Care Services Improvement Partnership2005.

8. Chapman M. Assi milating new s taff i n an i ntensive care nurse ry. N urse Management 1993;24:96B-H.

9. Williams A. The del ivery of qual ity nursi ng; a grounded theory st udy of th e nurse's perspective. Journal of Advanced Nursing 1998;27:808-16.

10. Badger J. A descriptiv e study of co ping strategi es used by MICU nurses during tra nsitions from cure- to comf ort oriented care. . Hear t and Lung 2005;34:63-8.

11. James N . Care = Organ isation + ph ysical labou r + emot ional labou r. Sociology of Health & Illness1992;14(4):488-509.

12. Sheldon T, Hewitt C, Lankshear A, Maynar d A, Smith K. Health servic e workforce and health outcomes; a scoping study. London: NCCSDO2005.

13. Mårtenson EK, Fägerski öld AM, Berterö CM. Observations of health-care professionals sharing and contributing responsibility in paediatric caring situations International Journal of Nursing Practice 2009;15:185-90

14. Georgiou A, Greenfield T, C allen J, Westbrook JI. Safety and Efficiency Considerations for the Introduc tion of Electronic Ordering in a Blood Bank. Archives of Pathology and Laboratory Medicine 2009;133(6):933-7.

15. Crocker C, Timmons S. The role of technology in crit ical car e nursing. Journal of Advanced Nursing 2009;65(1):52-61.

16. Manias E, Street A. Rethi nking ethnogra phy: recon structing nursing relationships. Methodological Issues in Nursing Research 2000;32:234-42.

17. Porter S, Ryan S. Breaking the boundaries between nursing and sociology: a critical reali st ethnogr aphy o f the theory-pr actice gap. Jour nal of Adva nced Nursing 1996;24(2):413-20.

18. De Lai ne M. Ethnography: Theo ry an d A pplications in Health Research. Sydney: Maclennan & Petty; 1997.

© Queen's Printer and Controller of HMSO 2010

19. Castle N. Measuring Staff Turnover in Nursing Homes. Gerontologist2006 April 1, 2006;46(2):210-9.

20. Gray A, Phillips V, Normand C. The costs of nursing turnover: evidence from the British National Health Service. Health Policy 1996;38(2):117-28.

21. Brodaty H, Draper B, Low L-F. Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. Journal of Advanced Nursing 2003;44(6):583-90.

22. All-Party Parliamentary Group on Dementia. Prepared to care: Challenging the dementia skills gap. London: Alzheimer's Society 2009.

23. Baker D, Gustafson S, Beaubien J, Salas E, Barach P. Medical Teamwork and Patient Safety. Agency for Healthcare Research and Quality: U.S. Department of Health and Human Services; 2005.

24. Gattuso S, Bevan C. Mother, daughter, patient, nurse: women's emotion work in aged care. Journal of Advanced Nursing 2000;31(4):892-9.

25. Mukamel DB, Temkin-Greener H, Delavan R, Peterson D R, Gross D, Kunitz S, et al. Team performance and risk-adjusted health outcomes in the Program of All-Inclusive Care for the Elderly (PACE). Gerontologist 2006;46(2):227-37.

26. Simpson A. The impact of team processes on psychiatric case management. Journal of Advanced Nursing 2007;60(4):409-18.

27. Hughes EC. Good people and dirty work Social Problems 1962;10(1):3-11.

28. Ashforth BE, Kreiner GE. "How can you do it?": Dirty work and the challenge of constructing a positive identity. Academy of Management Review 1999;24(3):413-34.

29. Jervis LL. The pollution of incontinence and the dirty work of caregiving in a U.S. nursing home. Medical Anthropology Quarterly 2001;15(1):84-99.

30. Stacey CL. Finding dignity in dirty work: The constraints and rewards of low-wage home care labour. Sociology of Health & Illness 2005;27(6):831-54.

31. Bolton S. Who cares? Offering emotion work as a 'gift' in the nursing labour process. Journal of Advanced Nursing 2000;32(3):580-6.

32. England P. Emerging theories of care work. Annual Review of Sociology2005;31:381-199.

33. Vinje H, Mittelmark M. Job engagement's paradoxical role in nurse burnout. Nursing and Health Sciences 2007;9:107-11.

34. Strauss A, Schatzman L, Bucher R, Ehrlich D, Satshin M. The hospital and its negotiated order. In: Friedson E, editor. The hospital in modem society. New York: Free Press; 1963. p. 147-69.

35. Morgan M, Calnan M, Manning N. Sociological Approaches to Health and Medicine. Scase R, editor. Breckenham: Croom Helm Ltd.; 1985.

36. Ward R, Vass A, Aggerwal N, Garfield C, Cybyk B. A different story: exploring patterns of communication in residential dementia care. Ageing and Society 2008;28:629-51.

37. Hochschild A. The Managed Heart: Commercialization of Human Feeling. Berkeley: University of California Press; 1983.

38. Brown Wilson C, Davies S, Nolan M. Developing personal relationships in care homes: Realising the contributions of staff, residents, and family members. Ageing and Society 009:1-23.

39. Sandberg J , Nol an M R, L undh U. ' Entering A New World': Em pathic Awareness as the Key to Posi tive Fami ly/Staff Relat ionships in Care Homes. International Journal of Nursing Studies 2002;39:507-15.

40. Lindgren CL, Murp hy AM. Nurses' and family members' perceptions of nursing home residents' needs. Journal of Gerontological Nursing 2002;28(8):45-53.

41. Gladstone JW, Dupuis SL, Wexler E. Ways that families engage with staff in long-term care facilities. Canadian Journal on Aging 2007;26(4):391-402.

42. Benbow S, Lennon S. Forget Me Not: Mental Health Services for Older People. London: Audit Commission 2000.

43. Philp I. Better health in old age. London: Department of Health 2004.

44. Social Services Inspectorate. Improving older people's services - policy into practice: the second p hase of ins pections in to older pe ople's serv ices. L ondon: Department of Health 2002.

45. Commission for Health Improvement. What CHI Has Found in Mental Health Trusts London: Department of Health 2003.

46. Bright L. Living well in later life. Nursing Older People 2006;18(4):13.

47. Philp I, Appl eby L. Securi ng better mental health for ol der adults. London: Department of Health; 2005.

48. Department of Heal th. Everybody ’s Business: Integrated Mental Health Services fo r O lder A dults:a se rvice de velopment guide. L ondon: Department of Health; 2005.

49. Naish J. Our health, our care, ou r say . Jou rnal of M edical Scr eening 2006;13(2):56-7.

50. National Institute for Health and Clinical Excellence, Social Care Institute for Excellence. D ementia - Su pporting people w ith demen tia an d th eir carers in health and social car e. London: Nation al In stitute for Healt h an d C linical Excellence; 2006.

51. Psychiatrists RC of. Who Cares Wi ns: Improving the Outcome for olde r people admitted to the general hospital : Guidelines for the development of a liaison mental health services for older people. London 2005.

52. Royal College of Psychiatrists. Raising the Standard: Specialist Services for Older People with Mental Illness London: Royal College of Psychiatrists 2006.

53. Banerjee S. The use of anti-psychotic medication for people with dementia: Time for action. London: Department of Health 2009.

54. Knapp M, Prince M. Dementia UK. London: Alzheimer’s Society 2007.

55. National Audi t Offi ce. Improving services and suppor t for people with dementia. London: National Audit Office 2007.

56. Department of Heal th. The essenc e of care: Patient-focused benchmarking for health care practitioners. London: Department of Health 2001.

57. Department of Health. Let's respect. London: Department of Health 2006.

58. Department of Health. New Ways of Working for Everyone - A best p ractice implementation guide. London: Department of Health 2007.

59. Brooker D. Person centred dementia care. London: Jessica Kingsley; 2007.

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60. Kitwood T. Dementia reconsidered: The person comes first. Buckingham: Open University Press; 1997.

61. McCormack B. Negotiating Partnerships with Older People: A Person-Centred Approach. Aldershot: Ashgate Publishing; 2001.

62. Nolan MR, Davies S, Grant G. Working with Older People and their Families: Key Issues in Policy and Practice. Buckingham: Open University Press; 2001.

63. Nolan MR, Davies S, Brown J, Keady J, Nolan J. Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers: The AGE IN (Advancing Gerontological Education in Nursing) Project. London: English National Board for Nursing, Midwifery and Health Visiting 2002.

64. MacKay CJ, Cousins R, Kelly PJ, Lee S, McCaig RH. 'Management Standards' and work-related stress in the UK: policy background and science Work and Stress 2004 April - June;18(2):91-112.

65. Department for Constitutional Affairs. Mental Capacity Act. London: HMSO; 2005.

66. Royal College of Nursing. Clinical supervision in the workplace. London: Royal College of Nursing 2002.

67. Department of Health. A vision for the future. London: Department of Health 1993.

68. Department of Health. Public health and clinical quality: clinical governance. London: Department of Health 2002.

69. Johnson R. A cross-national comparison of front-line care workers in care homes in Canada, Scotland and the US. IAGG World Congress of Gerontology and Geriatrics; 6th July; Paris, France 2009.

70. Emerson E, Barrett S, Bell C, Cummings R, McCool C, Toogood A, et al. Developing services for people with severe learning difficulties and challenging behaviour: Report of the early work of the Special Development Team in Kent 1987.

71. Department of Health. End of Life Care Strategy - promoting high quality care for all adults at the end of life. London: Department of Health 2008.

72. Woods R. Discovering the person with AD: cognitive, emotional and behavioural aspects. Ageing and Mental Health 2001;5(S1):S7-S16.

73. Holden U, Woods R. Positive approaches to dementia care. 3 ed. Edinburgh: Churchill-Livingstone; 1995.

74. Feil N. The validation breakthrough. Baltimore, MD: Health Professions Press; 1993.

75. Stokes G, Goudie F, editors. Working with dementia. Oxon: Winslow; 1990.

76. Burney-Puckett M. Sundown syndrome: etiology and measurement. Journal of Psychosocial Nursing and Mental Health Services 1996;34(5):40-3.

77. Department of Health, The NHS Constitution for England. Revised, March 2010.

78. Department of Health, Handbook to the NHS Constitution. Revised, March 2010.

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Appendix 1 Glossary

Activities of daily living (ADLs) – Include washing, dressing, using the toilet appropriately, feeding. People with dementia admitted to hospital wards may no longer have the ability to care for themselves or complete basic daily living tasks (2). The HCAs hold primary responsibility in assisting patients with their ADLs where required.

Care plan – Each patient has a care plan which identifies treatment to be received. Care plans are meant reviewed weekly by a multidisciplinary team (see *Ward round*). They are flexible and amended to patient's presentation and clinical need.

Challenging behaviour – Behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities (70).

Clinical supervision – Staff support system whereby groups or individuals are given the opportunity to talk confidentially about stresses and difficulties within the workplace.

Constant observation – Patient is accompanied and kept under observation at all times when in public spaces (dayroom, corridors, and so on) but not when in bedrooms, toilets or bathrooms, unless in need of assistance.

Dementia – Term used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. These can include Alzheimer's disease, vascular disease, dementia with Lewy bodies and fronto-temporal dementia (including Pick's disease). Symptoms of dementia include loss of memory, mood changes, and communication problems. In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people (2).

Dementia Care Mapping (DCM) – Observational tool designed to evaluate quality of care from the perspective of the person with dementia. Used in formal care settings such as hospitals, care homes and day care, DCM aims to empower staff to consider care from the point of view of the person with dementia through preparation and feedback (59). DCM is based on the philosophy of person-centred care introduced by Tom Kitwood (see definition below).

E-learning – Internet training programme completed on an ongoing basis when time permits on shift or at home.

End-of-life care – Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (71).

Essence of Care – A toolkit to help practitioners take a patient-focused and structured approach to sharing and comparing practice.

Functional services – Inpatient and other services for people presenting with functional mental health problems (i.e. not organic problems), including those who are over the age of 65.

Handover meetings – A routine meeting held at the commencement of each shift, handover involves a qualified nurse from the previous shift passing on updates and information to all staff for the next shift on each patient's presentation, wellbeing and activities or incidents.

Incident forms – Paperwork completed by an HCA and/or qualified nurse following serious incidents wherein patients or staff have been injured.

Intermittent observations – Patient checked every 10 minutes.

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Managing violence and aggression (MVA) – A certified five-day training programme, compulsory for all ward staff, which covers de-escalation skills, safe restraints, and breakaway techniques.

Mental Health Services for Older People (MHSOP) – NHS treatment and care for people aged 65 and over who are experiencing mental health problems, including conditions such as depression, anxiety, dementia and Alzheimer's disease.

Multidisciplinary team (MDT) – Includes all those who have direct involvement with patient care, treatment and progress, including doctors, managers, nurses, HCAs, social workers, psychologists, physiotherapists, and occupational therapists.

National Vocational Qualifications (NVQ) Health and Social Care Levels 2 and 3 – The aim of NVQs is to recognise the skills and competences of candidates in the workplace. Until a degree came to be required for nursing qualification, NVQs provided an alternative route to qualifying as a nurse.

Organic services – Inpatient and other services for people suffering from dementia/ presenting symptoms of dementia or delirium.

Person-centred care – First applied to dementia care by Tom Kitwood in the 1980s, person-centred care is a psychosocial approach which prioritises maintaining the personhood of people with dementia in the face of failing cognition (59, 60).

Physical observations – Measurements of patients' blood pressure, blood sugar levels and so on which are completed by qualified or nonqualified staff (depending on the ward).

Pro Re Nata (PRN) – Medication prescribed 'as the situation requires', that is, in addition to normal daily prescription, in times of severe distress, challenging behaviour, or poor sleeping patterns.

Psychosocial approaches – Interventions and therapeutic methods that aim to reduce distress resulting from neurological impairment and improve quality of life by creating an environment that supports the individuals' needs. Such approaches must be tailored to individuals' specific needs, personality, biography, goals and strengths (72). Examples include: reality orientation (73); validation therapy (74); and resolution therapy (75).

Restraint – The use or threat of force to help complete an act which the person resists, or the restriction of the person's liberty of movement, whether or not they resist. Restraint may only be used where it is necessary to protect the person from harm and is proportionate to the risk of harm (65).

Sundowning – Behaviour observed in patients with dementia associated with increased agitation and confusion that occurs in the late afternoon and evening (76).

Therapeutic activities – Interventions that aim to promote person-centred care, including creative activities (music, art, dance, or drama), cognitive stimulation therapy (an upgrade of reality orientation), and sensory stimulation (for example, through aromatherapy or massage) (59).

Ward round – Weekly meetings with the MDT wherein individual patients' care plans are reviewed, negotiated, and amended where necessary. Patients and informal carers are sometimes involved in ward rounds.

Working age dementia – Any person below the age of 65 diagnosed with dementia. Other terms include young people with dementia, early onset dementia, and work-age dementia.

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Appendix 2: Methods

Introduction

The focus of the main report is the health care assistants, and specific questions concerning their working lives. In this appendix we describe the data collection and analysis. The recording, organisation, coding and interpretation of qualitative data is a highly skilled and time-consuming aspect of ethnographic research. A thoroughgoing account of data analysis within the report might detract from its central questions; instead we offer this 'technical' appendix as a record of the processes which led to our inferences.

This appendix is presented in three sub-sections: first, a description of the research design is given as background. Secondly, we introduce the researchers, identifying the viewpoints they brought to the study. The role and contributions of the Project Advisory Group are also outlined. We conclude this appendix with a reflective account of the data collection and analysis. By making explicit the research process and the contributions of the individual researchers and the advisory group, our aim is to enable readers, if they so wish, to take these factors into account in appraising the results presented in this report.

Research design

The design of the study reported here is best described as 'team ethnography'. Three researchers adopted similar methods of participant observation in three different dementia assessment and treatment wards within the same health care organisation, initially for three months. The approach was deliberately transparent; staff were individually briefed before the research began, and posters were displayed on the wards to alert visitors that there was research in progress. Since patients were not the object of our observations, their consent was not required and given the nature of the wards we did not engage patients in the research.

The transparent approach to the data collection meant that the researchers were vulnerable to challenges and criticism from colleagues on the ward (e.g. of being 'a spy on the wall' – see Chapter 1). Anonymity was not an option, they worked side by side with the people whom they were studying, interviewed them face to face and then discussed the inferences of the research with them. This was a useful discipline in many ways. It meant that we had to justify our inferences fully and present them in a balanced way which was not only defensible but which also demonstrated an awareness of the complexities of the situations described. In this context, the approach which we unquestioningly adopted was characterised by an ethos of co-operation and constructive criticism, just as is practised in quality assurance in health and in higher education, the professional context for this study.

While the researchers were analysing data from the first three months of observations, the host mental health Trust contributed to the study the labour of its Dementia Care Mappers to permit a comparative analysis of life on the wards. These results, together with the observational data gathered by the researchers, informed our second phase of data collection. This phase entailed further participant observation as well as three focus groups, and 30 in-depth interviews with health care assistants, qualified nurses, and other staff on the wards. The usual conditions applied to this process: staff were assured that participation was voluntary, confidentiality was to be respected, and anonymity would be protected in reporting the data.

The focus groups and interviews provided an important opportunity to test out our preliminary analyses, to validate some findings and to gather informants' views on the study questions. With regard to the interviews, this stage allowed individuals to contribute information that they might not have wished to share with colleagues in a more public setting.

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A third phase of consultation and validation was included in the form of six, structured feedback sessions to staff. The script for these sessions is included in the main report. Unfortunately, attendance at these feedback sessions was low (six HCAs and six qualified nurses or activity co-ordinators), possibly due to shift patterns. Aware that there may still be unheard voices, especially dissenting voices, we circulated paper summaries of our findings to staff on the ward, with details of the study website and email addresses to which additional comments could be sent (with no results). At the suggestion of the Project Advisory Group, ward managers were interviewed to investigate whether they had any further reflections on the process; their views are contained in the main report.

Research team

Project Advisory Group
The study was devised by the lead applicant and planned with a group of clinicians, healthcare managers from the Trust, a workforce development representative and academics with experience of qualitative, applied healthcare research. Apart from a few individuals whose job changed in the interim, this group went on to become the Project Advisory Group, with the incorporation of two senior nurses with extensive experience of dementia care. Chaired by a former clinical director of the Trust in which the research took place, this group met five times in the course of the study to receive an account of progress and to offer advice on matters arising. Members of the group also participated in the recruitment of the researchers, their induction to the health service, training in qualitative methods, periodic mentoring of each researcher and consultations on the data analysis. Academic members continue to advise on the outputs of the study which are directed at peer-reviewed publications.

Ethnographers
The fieldwork team was composed of KS (aged 30), a female researcher from the United States with a background in social policy and the third sector; SB (also aged 30), a male researcher who had just completed a multi-sited ethnography for his doctoral dissertation in Education; and JL (aged 22), who had just completed her Master's degree in health psychology. They brought different academic interests, varying levels of research experience and confidence, distinct interpersonal skills and communication styles, different genders, even different accents, and each tended to notice different aspects of the setting and the HCA role. To illustrate these different perspectives, examples are taken from field notes written by each researcher wrote after an afternoon shift about halfway through Phase One.

Possibly a reflection of her disciplinary background, JL demonstrated acute awareness of interpersonal relationships between and among staff and patients on the ward, and she also had a good 'ear' for dialogue. In a reflective memo, she wrote: "I really enjoyed sitting with staff and having everyday chit-chat with them; it made me feel relaxed and included in the team… It's possible that this is why I was able to recall more conversational detail". As an example, she wrote:

As I was leaving the locker room, I bumped into H/CO, who was on her way in to collect her bag and head home after the early shift. H/LA was not far behind her and when they bumped into one another H/LA asked H/CO why she hadn't any make up on today. H/CO told her she couldn't be bothered this morning as she was so tired. H/LA told her she looked tired. H/CO said she had been on nights over the weekend, with a day off on Sunday and then back in today (Monday) on an early. She said she couldn't believe how little time they'd given her to recover from nights, but that she had a couple of days off now to rest.

The fine conversational detail recorded by JL could be 'mined' for nuances in the interactions between staff, as well as the substantial information about the job and extraneous factors conveyed in the conversations. In contrast, SB struggled to recall conversational details. However, his field notes reveal attention to detail about technical

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and procedural aspects of patient care and extensive reflection about his own experience of interacting with patients, especially in terms of assisting patients with meals and administering medications. Working on a ward designated to treat people with behavioural problems, he took particular interest in medication as it related to both patient care and the staff experience:

> *Q/LJ also mentioned [patient name], who she said has just been a different person since he was prescribed the diazepam. Q/LJ said that he will even say things like 'good morning' and 'how are you' when you wake him up in the morning. Apparently a similar therapy is being sought for [another patient], who is on trazodone [a psychoactive compound] at the moment, which I think is an anti-depressant rather than a sedative, and who can be an extreme challenge to get up in the morning, because he resists and fights all the way. … Almost all the patients are on typical anti-psychotics, which are usually strongly sedative, which could be seen as a form of 'prior restraint'.*

SB's prior awareness of the controversy surrounding aspects of medication (given his previous research in ADHD, in which medication is a key issue) clearly shaped his observations as a HCA and attuned his 'ear' to interaction between qualified nurses in the example given.

With a different academic background from SB and JL - applied research and social policy, KS tended to note more frequently how staff engaged with the organisational policies and procedures. For example, in the following field note, she highlighted two staff members' reactions to a new patient care initiative:

> *H/HN was talking quite heatedly about a new initiative, which is to provide patients the opportunity to choose their menu the day before. The topic came up, I gather, when [patient name] began loudly (and repetitively) announcing her evening's food choices to the room at large after looking at the menu posted on the board in the dining room – something which happens every day, as soon as the menu has been posted. "You're having a sandwich and chips, [patient name]" corrected H/HN, "don't you remember? That's what you ordered." [Patient name] didn't seem to comprehend that; she paused for a moment and then picked up her original mantra. H/HN and [the kitchen attendant] then discussed the inappropriateness of this initiative, since (a) patients forget what they chose and (b) "there are always choices on that meal cart" (kitchen attendant) and "there's always* <u>something</u> *on that meal cart I would choose to eat" (H/HN). "Don't break what's not broken, is what I say", H/HN went on.*

This note provides insight into how staff engaged with the initiatives that constructed their roles, and while it contains some direct quotations, other parts of the conversation are summarised, reducing them to the points which were salient in that context.

In summary then, the researchers' perspectives were defined not only by their vantage points in their respective wards, but also by the education and experience which they brought to their observations. The particular biases introduced in this way were evident in the joint analysis process described below. Recognising the differences and building on the individual strengths of the ethnographers, the final report strives to integrate all three perspectives.

Data collection and analysis

First phase

Researchers kept detailed field notes during the first phase of data collection, during which they spent roughly half their time working on the wards. A standardised, two-column system was developed for recording these field notes, such that they were written in parallel; observations were written in the first column and related reflections in the

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second. An account of this first phase written by KS states that '[a]lthough this was a team ethnography, the three researchers effectively followed the classic 'lone ethnographer' model throughout the first phase of data collection. Taking the grounded theory approach, our conscientious intention was to generate data from which we could inductively draw theoretical propositions about the challenges and rewards of the HCA role. Therefore, we did not set parameters for data collection in advance; nor did we systematically share our observations throughout Phase One, in order to avoid imposing a pre-emptive interpretive frame on each other's impressions and interpretations.'

By January 2009, when the first phase of data collection was complete, each researcher had amassed many pages of field notes. These were analysed using a grounded theory approach (Strauss and Corbin, 1990). Grounded theory aims to eliminate pre-conceptions about a research field, by eliciting frameworks for understanding from the data, rather than imposing them on the data. Strauss and Corbin identify three stages of analysis: open coding, axial coding and the coding of selected episodes. The mechanism used for coding is referred to as 'constant comparison', which describes the inductive process. In open coding this means that topics and themes that occur repeatedly are identified and classified, then newly-occurring topics are added to the list until fresh data bring no new concepts. A similar approach is used in the next stage, to identify concepts that link sets of topics (axial codes). Constant comparison also involves checking back to ascertain that the emerging codes are reduced to minimum number while at the same time being comprehensive with regard to the data. Both newly-acquired data and existing data are subjected to the process of comparison. The codes are linked, ranked in order of importance to identify dominant concepts (selective coding) and checked until a meaningful framework emerges which can be applied to summarise the data.

The ethnographers met intensively to code the field notes line-by-line using NVivo8 software, generating about 170 open codes through the constant comparison approach with the aim of reducing the data to meaningful sub-sets. Once about a third of the field notes had been coded, the available codes needed no further additions, and the researchers divided up the remaining field notes, swapping roles between paper-based and NVivo coding (so that each note was coded once, then checked by a second researcher). This was to retain an ongoing dialogue about the process as well as to ensure inter-coder reliability.

In the next stage of the analysis, the researchers worked collaboratively to build 'trees' of inter-related, open codes, examples of which are given in Figure 1. This analytical process was recorded in 'memos' which drew on supporting data from the field notes. These memos represent detailed summaries of 22 broad topics (Table 1).

Second phase

Dementia Care Mapping

While the researchers were engaged in the first phase of analysis, trained staff from the health Trust carried out Dementia Care Mapping (DCM), which is a systematic approach to observing and rating staff-patient interactions in an institutional setting (Kitwood and Bredin, 1994) at the three study sites. The DCM data proved inadequate for meaningful statistical analysis, due to a shortfall in the amount of data collected; a proportion of patients being 'mapped' were removed from the setting for clinical investigations in the hospital which meant that the minimum of 4 hours of observation per subject was not achieved. Consequently, statistical analysis of the data would be unreliable. Nevertheless, the exercise did reveal striking differences between the wards, and the discussion about the results sensitised the researchers to quality of care issues which they had not considered previously:

I think some of the things I am seeing – such as talking over – were always there, but I didn't pick up on them to any great extent. (Ward B, Phase Two reflections)

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The DCM approach, which measures staff-patient interaction, clearly informed the researchers' approach to the second phase of observation:

I can't quite figure [HCA] out; she has a very dry sense of humour, combined with what appears to be a lack of enthusiasm or demonstrable concern for the patients. She has done the job for some time, and seems to know everyone and everything, she is very efficient also, and certainly not unfriendly – when she does interact with patients it is on a nice, close and personal level – she just doesn't appear to do so very often. (Ward B, Phase Two reflections)

Observational data

The memos and the collaborative analysis of field notes outlined above were also brought to bear on the second phase of observation, in the form of specific questions to explore. For instance, one researcher had noted many different examples of humour and teasing between staff on the ward. In the second data collection phase, the others set out to seek similar data from their wards, if available, and all researchers agreed to note the different functions which humour seemed to fulfil in the study context. The following reflection shows the shift in perspective:

Jokes, teasing, and/or laughter weave through almost every circumstance and interaction on the ward: sometimes as overt and defining elements, at other times as a subtle undercurrent or a single conversational bracket. During the second phase of participant observation on Ward A, I made a concerted effort to identify and record specific examples in order to better understand when, where and how humour is manifest. This was a difficult task given humour's prevalence – rather like trying to isolate individual raindrops in a deluge. (Ward A, Phase Two reflections)

It appears that this researcher did not record many examples of humour during Phase One because of its very *prevalence*, rather than its scarcity. Without comparison against JL's notes, she might have missed the significance of humour entirely. Instead, she was able to identify specific examples of its prevalence and function on the ward.

Another researcher recorded more nuanced observations about who participated in humour on the ward and to what extent, noting that humour between staff and patients was at times inclusive of patients, at other times exploitive. These fieldnotes point out that "humour can cover a stressful situation means that it risks effacing the possible injustice/distress from which the stress emerged", and offer further layers of meaning and interpretation.

Humour is an example of a phenomenon which was widely-observed but which we only include in the main report in relation to a higher-order phenomenon: team working and the inter-personal relationships it entails. This choice reflects the fact that the original research questions shaped what we addressed in the main report. The valuable insights which are less central to these questions are also expected to be placed in the public domain via other outputs, in particular publications in relevant academic journals concerned with research methodology and qualitative approaches to health research.

By contrast, in the main report we do explore the concepts of engagement and detachment because they were more proximally related to HCAs' working styles. Both topics generated memos in our analysis of the field notes and these were clearly inter-related. Therefore, in the second phase we sought further understanding of engagement or detachment, in particular whether they could happen simultaneously, and what differences were found between individual staff in their demonstration of engagement and detachment. The process of distillation and comparison of data collected in the three sites during the first phase provided a valuable foundation for further data collection:

Looking back, in Phase One I felt there was strong empathy on the ward and that staff really did understand that the patients are going through a tormenting time. This was

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evident in many of their on-shift conversations. However, in Phase Two, whilst I still witnessed this empathy, I saw how this understanding is not always translated into empathic care by those who claim to feel for the patient in handover/ break times and this allowed me to reflect on similar instances from Phase One which had not originally recognised as significant. For example, looking back to my previous time on the ward, I am reminded of the way in which HCAs empathised with [patient's name] in handover and on breaks about her husband's departure, cheating, her divorce and so on, but in her presence they rolled their eyes about her when she approached staff with all the questions, worries and confusion they had previously claimed to understand.
(Ward C reflections on Phase Two)

Table 1: Memo topics

1. Communication with patients
2. Staff relationships
3. Attachment
4. Detachment
5. Acceptance
6. Job-life interface
7. Skills
8. Family/friends of patients
9. Routine
10. Challenging behavior
11. Resources
12. Rota
13. Patient management
14. Relationship to "management"
15. Identity management: Us versus them
16. Individual in role
17. The team
18. Person-centred care
19. Shift characterisation
20. Cigarettes and alcohol
21. Methods and approaches
22. Suitability of patient

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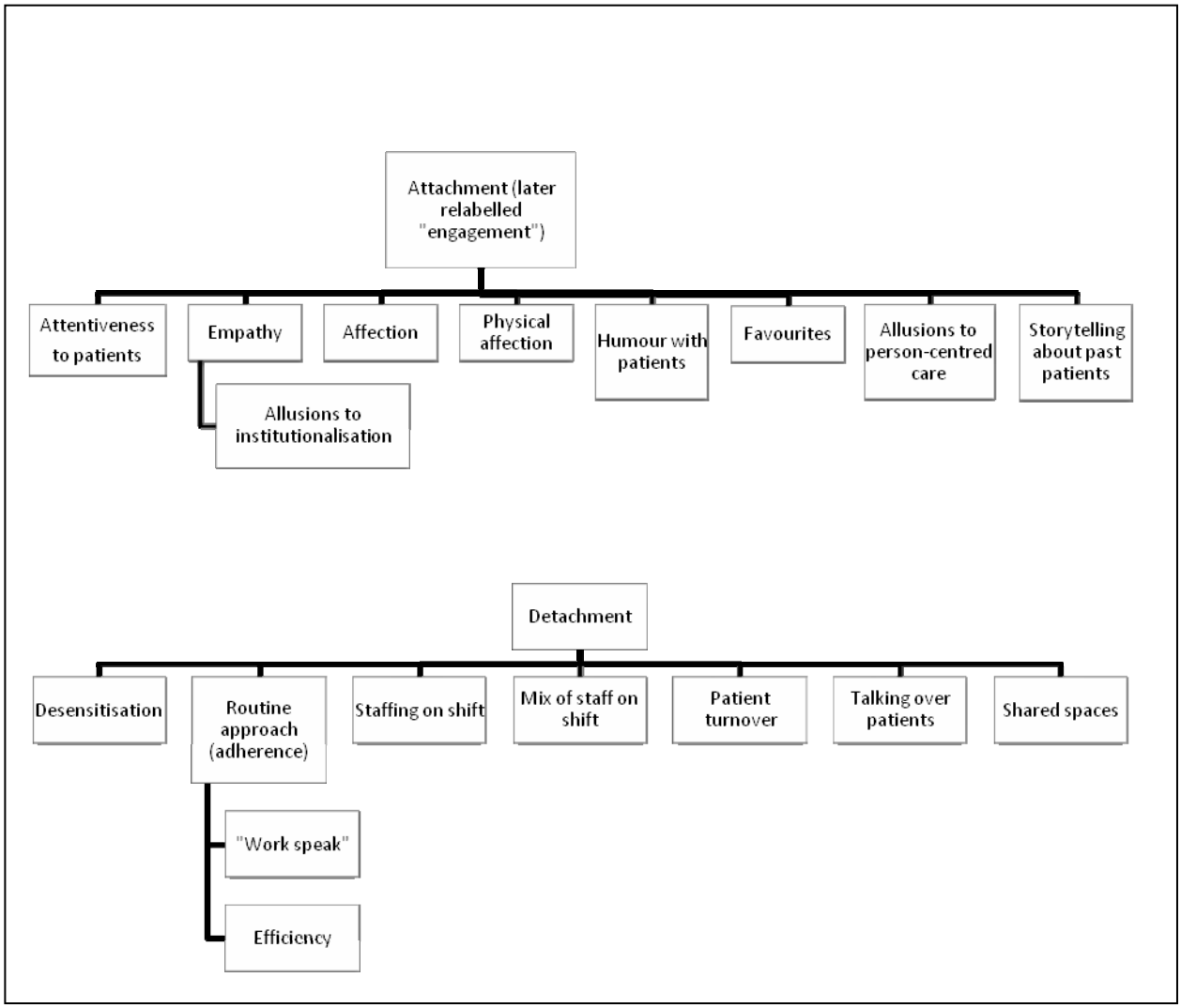
Figure 1: Examples of coding 'trees' for memos



Interviews
The questions developed for the focus groups and interviews were based on the evidence from the first phase of data collection and subsequent analysis. The individual interviews were undertaken first; their timing was 'dovetailed' with the researchers' re-insertion to the ward, when they resumed duties as HCAs for about one month to validate analysis of Phase One data and to collect new observations. During this period they recruited their colleagues to participate in the individual interviews, which were held subsequently. The schedule was developed from preliminary analyses and structured around the study questions:

- What motivates staff?
- What obstacles to good care do they face?
- What do they find stressful and how do they cope?
- What appears to promote staff wellbeing?
- What differences exist between different groups of staff?
- What are the implications of these findings for person-centred care, which is set as a standard of good practice?

A 'concept guide' to the questions, which displays their rationale is in Table 2.

Fifteen HCAs and 13 qualified nurses including two ward managers were interviewed in person, as well as two 'other' staff (roles not specified to protect confidentiality). While the researchers' participant observation as HCAs portrayed the actions and expressed attitudes of the staff, the interviews were designed to investigate their motivations, their concerns and how they made sense of the work they did. Of course, in interpreting these interviews we need to be aware that there are strong social rules governing self-presentation in a structured setting, such as a research interview at work. Despite this, we found that the relationship established between the researcher and the colleague interviewed, which included shared terms of reference and experiences, enabled a frank and sympathetic exchange, as evidenced by the reflections set down by one researcher (Box 1)

Focus groups
One focus group was held in each ward; there was no demand for additional groups. We interpreted this as a sign that staff felt their voices had been heard adequately through individual interviews and while interacting with the researcher in the HCA role. Moreover, in effect, much focus-group-like data had already been collected in group settings during the participant observation, as described by KS:

… within the team milieu, of which we were a constant feature for several months, staff spend a great deal of time talking about, complaining about, laughing about, and reflecting on their jobs - while they work, on their breaks, at social events… there was not so much need to bring them together in a formal way to have essentially the same discussions, especially on Ward A when almost all of the staff had also participated in pretty long individual interviews – the one focus group that I held seemed quite redundant (i.e. didn't generate any new information), though it was useful for capturing verbatim the kinds of things I'd been hearing staff say for months.

Two focus groups were held with informal carers of people with dementia, convened by the local Alzheimer's Society in April, 2009. This step was included to obtain an informed but independent perspective on the wards, from relatives of former patients in these or other inpatient settings. Two researchers were present at both focus groups as well as a representative from the Alzheimer's society. Attendance was of course voluntary and each focus group included six current or past carers for someone with dementia. The meetings were digitally recorded and transcribed. The first group was a mix of past and current carers, some of whom had hospital care, others of home care and care homes. The second group were all current carers of people in day centres or home care.

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Box 1 Interview Reflections: Ward A

The first thing that I did was corner the ward manager, tentatively, to gain her approval to proceed…. [S]he responded immediately with practical suggestions (i.e. interview a couple of staff during the early shift, another couple during the late shift, and do focus groups during handover – 'At that rate, you'll be done in a couple of days!'). …Notwithstanding this promising start, my first couple of attempts to conduct interviews fell flat. During that first week, one of the patients had been moved upstairs to a medical ward and required constant monitoring due to extreme agitation, which left the ward down one HCA. There also happened to be a full and particularly restive complement of patients on the ward, which was matched by higher levels of stress and short tempers among the staff. … However, the third time I visited the ward, the winds changed again. … [m]y first day of interviews was a bank holiday, which was fortuitous because it meant the ward felt quieter and more relaxed than it might have on an ordinary weekday. …

HCA11 was the only respondent whose initial reluctance to participate carried over into the interview itself – she was uncomfortable throughout the entire interview, and I wasn't successful in my attempts to plumb her thoughts and opinions. …

Conducting interviews with known respondents, alongside whom I had already worked for several months (and socialised with outside work, to a limited extent), was an interesting and complex experience. On the one hand, I am confident that the respondents were more willing to engage with me than they would have been with an unknown researcher – this was clear to me from their relative comfort in the interview setting (with the exception of HCA11, as mentioned); from their ability to reference our shared understanding of the tasks, the patients, and the other staff (often punctuating statements with 'well, as you know yourself…'); and from explicit comments, such as from HCAN1 who said of the other HCAs 'you know, they wouldn't do [these interviews] if they didn't already know you and like you.' Furthermore, I would venture to say that this foundation of mutual trust and respect allowed the interviews to be a fairly positive experience for most of the respondents – several of whom said at the end, usually with some surprise, that it had been 'quite good' or 'interesting' to talk about their work.

Given that I already had a fairly well-established relationship with each of the respondents, I conducted the interviews in a deliberately conversational, interactive manner – sharing my own experiences, referencing things that I knew or had observed about the particular respondent, and so on. This seemed the natural (and most effective) way to proceed, whereas to step back into a neutral, detached, 'objective' researcher role would have felt contrived and disingenuous. On the other hand, however, there are negative implications of this informal and interactive approach, namely: it is possible that the respondents structured their responses according to what they believed I wanted to hear; and it is also possible that, by implicitly (rather than deliberately) assuming we shared the same understanding or predicting what a certain respondent might say, I failed to tease out deeper meanings.

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Synthesising the findings

Interviews and focus groups were all transcribed. These transcripts together with the fieldnotes from Phase Two, were coded line-by-line by two researchers, as with first phase (in order to maintain inter-coder reliability). The researchers met periodically with the principal investigator and to discuss how the findings from second phase shaped the emergent findings from the first. The key memos were elaborated, and developed into chapters which responded to our research questions. Each author of the final report contributed to refining a particular area of the analysis, incorporating findings from the first and second phases of data collection. The introductory chapter 'First Impressions' was refined first and circulated to the Project Advisory Group members, as a litmus test of how our findings would be received, in particular by those with managerial responsibility and accountability in the Trust. These excerpts included the hardest-hitting field notes, and we were only asked to consider one change, which was the inclusion of two words in a direct quotation that might cause offence; we therefore replaced this with an indirect euphemism, but no other changes were made.

In light of the original research questions and the findings from the data analysis, and fully cognisant that we would be delivering our conclusions to the staff whom we had observed, the research team met to draft the final report and identify key messages and questions arising from it. Each researcher took the lead for one or two chapters, and the chief investigator took overall responsibility for drawing these elements into a coherent whole. Finally, the feedback to the staff themselves was written down to ensure consistency, and circulated to managers before it was delivered verbally to the people who attended the feedback sessions.

The production of the report to the SDO addressed the main study questions but clearly, the research process and the fieldnotes generated by the researchers can be put to other purposes, such as academic papers, conference presentations and other forms of knowledge exchange. In one sense, the methodology is still evolving, and any account of it must remain open-ended until the many potential applications of the data are exhausted.

References

Kitwood, T. and Bredin, A. (1994) Evaluating dementia care: The DCM method. Bradford Dementia Research Group, Bradford University, Bradford.

Strauss, A. L., & Corbin, J. (1997). *Grounded Theory in Practice*. London: Sage.

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Table 2: Concept guide to individual interviews with staff

1. SKILLS AND TRAINING

➢ The job itself

- *Tell me about your job – what, as an HCA, do you* do*? (list all tasks and responsibilities)*
- *Have you ever had to… take a blood pressure reading, perform an enema, change a wound dressing?*
- *What skills do you think are important/ necessary to perform this wide range of tasks?*

WHY?
- Solicit full description of job as perceived and prioritised by the HCAs themselves
- Get a sense of the *range* of HCAs' knowledge and skills, including more specific/ technical know-how
- Learn staff's own definition of the skill-set required (to be the ideal worker)

➢ Job training

- *How did you learn to do all of these different tasks? (Formal training, in-house training, self-study?)*
- *How well do you think your training prepared you for this job?*
- *Has training helped you improve in your role?*
- *Are you ever asked or required to do things that you don't feel trained or qualified to do?*
- *Can you think of any specific gaps in your job training?*
- *How could job training be improved? Would you like to receive more or less training?*
- *Do you see yourself as moving up or on from this work to other positions? How?*

WHY?
- Do staff feel they were adequately prepared for this job in advance?
- Learn about job training, including: experience of, attitudes about, usefulness of, gaps in
- Does training feed into performance improvement over time?
- Do staff see opportunities for professional development, onward and upward?

➢ Job role

- *Do you think different people approach the job in different ways? If so, in what ways?*
- *What type of work approach do* you *take? (Pick from researcher-identified types)*
- *What personal characteristics do you think people need to do this job?*

WHY?
- Sense of self in role – what kind of worker HCAs see themselves as, in comparison to others who take different approaches
- What "type" of person required for this role

2. REWARDS AND JOB SATISFACTION

➢ Rewards and job satisfaction

- *Why do you do this job?*
- *Are there certain aspects of the job that you find rewarding?*
- *What keeps you going? What motivates you to come in for each shift?*
- *Are you content in your job?*
- *Would you say you feel an overall sense of job satisfaction? Describe why or why not.*
- *Is financial compensation the primary reason for doing this job? Is it a sufficient reason?*

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- *[Retrospectively] Do you think your sense of satisfaction in this job has changed over time? In what ways?*
- *[Looking ahead] How long do you see yourself doing this job? Can you imagine that your feelings of job satisfaction/dissatisfaction will change over time? In what ways?*
- *Can you* imagine *other ways to get job satisfaction or a sense of reward from your work? Would it be easier to find the job rewarding if… ??*

WHY?
- Positive perspective on the job – understanding how staff see the rewards of their role
- Understanding how support needs change over time
- Possibly identifying obstacles to greater job satisfaction

3. Challenges

➢ Hard work

- *Can you remember back to when you started – how long did it take you to get used to this job? Was it hard to adjust? (Use personal experience as researcher)*
- *What do you think is the hardest thing about this job?*
- *What do you dislike most about this job?*
- *How do you deal with the most difficult aspect(s) of this job?*
- *Are there aspects of the job that you think* other people *might find difficult – even though you don't?*
- *Is there any task that you* won't *do – that you'd rather let someone else take care of instead?*

WHY?
- Understanding challenges of the job overall
- Identifying which specific challenges are faced by specific workers

➢ Emotional labour

- *Would you say that you are emotionally attached to this job? In what ways? (To patients, to co-workers, to ward overall)*
- *Do you think that you are emotionally attached to the patients on the ward? Is it possible to become emotionally attached to patients with advanced dementia? Why or why not?*
- *Are there limits to how emotionally involved you are or can be in this job? Describe these limits.*
- *Do you notice that you sometimes "detach" or distance yourself emotionally from this job? When does that happen? Why? Do you notice it happening in other staff?*

WHY?
- Do staff recognise own attachment/detachment?
- Can they explain why attachment/detachment is necessary?
- How they value attachment versus detachment

➢ "Challenging" behaviour

- *What do you find particularly challenging about dealing with the patients on this ward?*
- *What would you describe as "challenging behaviour", i.e. what do patients* do *or* not do *that makes your job harder?(e.g. physical attacks, poor communication, lack of mobility)*
- *Is "challenging behaviour" common on this ward?*
- *What do you do about "challenging behaviour"?*
- *What do you think are appropriate responses to challenging behaviour? Inappropriate?*
- *In your experience, is it possible to predict/ avert challenging behaviour – or is it inevitable?*

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- *Do you ever feel scared when working on the ward – physically or emotionally threatened?*
- *Do you think patients on this ward can ever be held responsible for their behaviour? If so, when? Can they ever improve their behaviour?*

WHY?
- How staff define "challenging" behaviour or patients
- How much "challenging behaviour" affects their job
- To what extent they reflect on different methods for dealing with challenging patients
- How much staff see themselves as influencing vs managing patient behaviour
- Do they hold patients accountable for their actions and behaviour?

➢ **Death and dying**

- *How often do you have to deal with* death *as part of your job?*
- *How do you feel about caring for people who are dying?*
- *What happens on the ward when someone is dying? What do you think* should *happen?*

WHY?
- How much death and dying impacts the HCAs' role
- Is patient death a salient feature of job experience?
- Do staff have opinions on end-of-life care?

➢ **Switching off, leaving the work behind**

- *How easy (or difficult) do you find it to "switch off" when you leave the ward at the end of your shift? (Refer to researcher experience)*
- *What strategies do you use to "switch off"?*
- *What makes it difficult to "switch off"?*
- *Do you think it becomes easier or harder over time – the longer you spend in this job – to "switch off" from it?*

WHY?
- How staff negotiate the boundaries between work and home life
- Does work impact home life, to what extent, and in what ways?
- What are the obstacles to successful maintenance of work-home separation?

4. Social relations and support

➢ **The staff team**

- *How would you describe the way that the staff work together on this ward?*
- *Does everyone work together equally, or would you say there are divisions or cliques within the staff team?*
- *Do you feel included in the staff team? To what extent? Is it important to you to feel included?*
- *Do you feel close to your co-workers? To what extent?*
- *How does the job help or hinder you in forming close relationships with your co-workers?*
- *How do you benefit (or not) from your relationships with your co-workers?*
- *Do you ever tease or get teased by co-workers? How do you feel about teasing?*
- *Do you think the management of the ward affects how everyone works together? In what ways?*
- *Do you socialise with your co-workers outside work? How often?*

WHY?
- How individual staff members perceive and experience "the team"
- The importance of relationships with co-workers

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- Perceptions about management's role in organising relationships with co-workers (positive or negative influence)

➢ **Stress**

- *What makes you feel stressed or unhappy about your job?*
- *What do you do when you feel stressed/ unhappy about your job? How do you deal with those emotions? (Who do you talk to – or not? Do you vent the emotions – or not?)*
- *Have you ever considered leaving the job? Why or why not? (Specific examples?)*

WHY?
- Self-characterisation of job stress (in case it hasn't come out explicitly by now)
- Strategies for dealing with stress

➢ **Support**

- *If you are feeling stressed or unhappy about your job, what support can you find within the organisation, i.e. on the ward and within the larger structure of the Trust?*
- *Have you ever accessed this type of support – or would you in future?*
- *Do you think there are other things the Trust could do to support you in this job?*
- *If you are feeling stressed or unhappy about your job, who do you turn to for support outside work?*
- *Do you ever find it hard to get this kind of support?*

WHY?
- Do staff know about, access, approve of mechanisms for job support within the Trust?
- Ideas for other support mechanisms
- Do staff share the perception that "no-one else understands" what it's like to do their job – or do they find understanding and support from family, friends, community?

5. CONTEXT OF CARE

➢ **Meanings of "person-centred care"**

- *How would you define "person-centred care"? What does it* look like *in terms of patient care?*
- *What do you think are the challenges of taking a person-centred care approach? Are there limits to this approach?*
- *Can you think about what would make it easier to take a person-centred care approach?*

WHY?
- Understanding and uptake of person-centred care
- Obstacles to practising person-centred care

6. CHANGES

➢ **Changes**

- *How much would you say you complain about your job?*
- *Why do you complain about your job – what's the point?*
- *Do you see anything changing on the wards? If so, what? In future?*
- *How much do you feel that your opinion or knowledge is taken into account when changes are made on the ward? Small changes to patient care? Big changes like refurbishment or reorganisation?*
- *What would you* really *like to see change on the wards?*
- *Is there anything you'd like to see change about your own job?*

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WHY?

- What is the point of complaining – it is cathartic activity in and of itself, or does it require better institutional response?
- Extent to which staff feel included in decision making
- Issues that staff are most concerned about with regards to the big picture
- Issues that concern staff most about their own jobs

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Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.