Feature Article

Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community nurses, residents and their families

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A B S T R A C T

This study uses the Framework approach to qualitative analysis to explore and compare the views of residents in care homes for older people, their families and care providers on maintaining dignity. We interviewed 33 care home managers, 29 care assistants, 18 care home nurses, 10 community nurses, 16 residents and 15 members of residents’ families. The most prevalent themes were: “independence,” and “privacy”; followed by “comfort and care,” “individuality,” “respect,” “communication,” “physical appearance” and “being seen as human.” Residents and their families sometimes described incidents where a resident’s dignity had been compromised. How to help residents maintain dignity and focusing on fostering dignity, can be a starting point for improving the quality of care and quality of life of residents. It is, however, important to remove the gap between the rhetoric of dignity conserving care and the reality experienced by residents in these and other care settings.

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In the UK, and in many other countries, older people are increasingly cared for in long-term care facilities such as care homes. These are collective institutional settings where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time. The care provided includes on site provision of personal assistance with activities of daily living. Nursing and medical care may be provided by on-site nurses employed by the home (in nursing homes) and medical professionals working from an organization external to the setting. Residents are often heavily reliant on staff for their care, which can erode their sense of dignity. Loss of dignity remains a major issue in the lives of older people in many countries. Although dignity is an important aspect of quality of life for residents, and a strong predictor of residents’ satisfaction with their care, concerns have been raised about loss of dignity in care settings. Several qualitative studies have explored the construct of dignity from the perspective of care home residents, however, there has been no comparison between the views of residents and those who provide their care in this setting.

Respect, including both respect from others and for oneself and maintaining independence are important for maintaining dignity in older people. A previous study exploring dignity in hospital settings found privacy and communication to also be important. Additionally, qualitative studies have explored the views on dignity of older people in care homes. A German study showed that not being a burden was important to residents, and that their sense of dignity was threatened by illness and care needs. A Swedish study described three main themes: the unrecognizable body (loss of function and control); fragility and dependency; and inner strength and a sense of coherence. A study conducted in the UK found support for three broad themes in Chochinov’s dignity model: illness-related concerns (level of independence and symptom distress); dignity conserving repertoire (perspectives and practices); and social aspects of the illness experience (social concerns or relationship dynamics which can erode or bolster a person’s sense of dignity). Although these studies give some insight into aspects of care that residents feel could help them maintain dignity, the views of health care providers are of vital importance to understand which aspects of the care residents receive are likely to impact on their sense of dignity, since loss of dignity remains a major issue in the lives of older people in many European countries, and concerns have been raised about loss of dignity in care settings. The aim of this study is to explore and compare the views of care providers, residents and their families on dignity and how to maintain it.
Methods

Study design

We used qualitative descriptive methods\(^\text{15}\) to enable us to explore participants’ views in depth.

Ethical approval

The study was approved by the Kings College Hospital Research Ethics Committee (REC Ref: 07/H0808/136; 07/Q0703/89) and met local research governance requirements.

Sampling and recruitment

Our sample was 34/38 of the care homes for older people in two areas of London UK (two homes were closing down, and two homes were too busy to take part). In each home we planned to recruit: the manager (\(n = 34\)), a care assistant (\(n = 34\)), a nurse in homes employing an on-site nurse (\(n = 18\)), community nurses who visited the care homes not providing on-site nursing (\(n = 10\)), care home residents (\(n = 20\)), and a family member who had regular contact with the resident (\(n = 25\)). We aimed to recruit five family members to represent residents with dementia who could not be interviewed. Care home managers are in day-to-day charge of the regulated services provided at the care home, nurses provide medical care and care assistants provide personal care under the guidance of qualified health care professionals. It was not feasible to ask managers to provide the details of their staff and residents needed for purposeful or maximum variation sampling, therefore, we used a random numbers table to select care assistants and nurses employed by homes from staff lists, and community nurses (from the centers where they worked). We recruited a convenience sample of residents and their families from eight care homes willing to help us with this aspect of the study. These homes varied on the following criteria: size, whether or not they were registered for nursing, and whether or not they were taking part in a national quality assurance program (Gold Standards Framework for Care Homes). We invited all residents whom managers felt were willing and able to take part, along with a close family member (if they had one).

Interviews

We conducted semi-structured interviews with participants in the home or facility based settings, depending on their work or living situation. Before commencing any interview, the interviewer checked participant’s understanding of the study, answered any questions and obtained written informed consent. All participants were first asked “What does the word dignity mean to you?” followed by the following prompts: “What do you think supports a resident’s sense of dignity?”; “What do you think undermines a resident’s sense of dignity?”, and “What can you do to support a resident’s sense of dignity?” Most interviews were audio-recorded and transcribed verbatim, however, four managers, two care assistants, and one community nurse preferred not to be recorded. In these cases the interviewer took detailed notes during the interview, which were sent to the participant for validation. Demographic characteristics of participants (gender, ethnicity and age) were collected for each participant from care home staff. All participants were compensated with a £20 gift voucher for their time.

Analysis

Our analysis was based on the Framework approach to qualitative analysis.\(^\text{16}\) This comprehensive, dynamic, flexible approach to qualitative analysis can be used for studies which are more descriptive than interpretative, and is particularly suitable for comparing different groups. Both authors read the interview transcripts to familiarize themselves with the data and to identify recurrent themes. They compared and discussed themes, re-reading transcripts until they reached agreement. The themes were developed into a thematic framework, which included examples of text from the six participant groups. The transcripts were indexed (coded), using theme names and participant group. Sections of text relating to more than one theme were coded under each theme. The data were recorded in a chart so that the themes in each group could be counted and compared, and the range of responses within each theme described. The chart contained summaries of the indexed text. The data was analyzed independently and systematically by two authors and any discrepancies were resolved by discussion. Since we were interested in preserving participants’ descriptions, we stayed close to the text, rather than transforming them into a more abstract interpretation of meanings, therefore, our analysis was more descriptive than interpretative.\(^\text{15}\) We present the number of participants endorsing each theme to enable us to compare the views of the different groups in our study (Table 2).

Results

Response rates and demographics

Response rates were: 33/33 for managers (one managed two homes); 29/50 for care assistants; 18/28 for nurses employed by the homes; 10/20 for community nurses; 16/41 for residents; and 15/46 for residents’ family members (eight representing residents with dementia). The number of people invited to take part varied. Recruitment depended on help from busy care home managers and was slower than expected, consequently, we were unable to recruit care assistants in five of the homes, or the planned

<table>
<thead>
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<th>Table 1 Characteristics of participants.</th>
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<tr>
<td><strong>Managers</strong>,</td>
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<td>(n = 33)</td>
</tr>
<tr>
<td><strong>Sex</strong> (frequency)</td>
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<td>Female</td>
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<td>Male</td>
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<td><strong>Ethnicity</strong> (frequency)</td>
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<tr>
<td>White</td>
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<td>Asian/Asian British</td>
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<td>Black/African/Caribbean/Black British</td>
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<td>Not given</td>
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<td><strong>Age (median (range))</strong></td>
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<td>56.0 (35–68)</td>
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number of residents and their families, during the data collection period of the study. Characteristics of participants are in Table 1.

Themes

The themes and their prevalence are shown in Table 2. We selected quotes to illustrate the views from each group for each theme. Overall, the most prevalent themes were “independence, autonomy, choice and control” and “privacy.”

Independence, autonomy, choice and control

Independence, autonomy, choice and control are related concepts concerning self-determination (not being restrained, influenced or coerced by others) and not relying on others for aid or support. This theme was the most highly prevalent in all groups except for community nurses, who focused more on the importance of providing comfort and care. Care home staff spoke of giving residents choice and control in a variety of situations: their personal care and whether this is provided by a care-giver of the same sex or not; who is present when giving personal or medical care; their clothing; whether their families are consulted about their care; the layout of their room; food; leisure activities; and religious and cultural practices and preferences. Although the importance of asking residents’ permission (e.g. before giving personal or medical care) was mentioned, the notion of choice could become problematic when staff felt that residents had made choices which could damage their health. There were several examples of care home staff trying to persuade or negotiate with residents so that their choices were deemed reasonable by staff. Although staff felt that it was acceptable for residents to make some “odd” choices, there was some tension between “independence, autonomy, choice and control” and the need for residents to obey care home rules to ensure their safety, particularly for residents with cognitive impairment.

“Sometimes you have to call in district nurses or doctors. We have a lady that hates them coming in, but sometimes we have to override her when she’s breaking out in pressure sores and stuff — so nine times out of ten her dignity does go out of the window… Just tell them, you know, it’s best for them to have it seen to, or… you just tend to sit there and talk to them. Most of the time, and nine times out of ten, they do come round.” (Care assistant:CH12)

“Say somebody’s got dementia would like to walk down the road and they want to go on their own, which would be risky in terms of getting lost, getting hit down by traffic — because they can’t, um, comprehend the difference between safe/the unsafe situation…” (Manager:CH19)

Several of the residents’ family members raised concerns that staff were undermining residents’ choices, and one care home manager suggested that although staff talked about the importance of residents’ rights, they “paid lip service to choice” (Manager:CH15). An incident described by a residents’ daughter suggests that staff sometimes thwarted choice to reduce their workload rather than protect residents.

“I complained about two particular individuals — they sort of insisted that she walked to the dining room, when this particular day she didn’t feel like — she wanted her lunch in her room… and she said she wasn’t well… One of them said something like… they would withdraw her medication — this was a carer said this, that she was a doctor, and she was backed by another one. I mean they might just have been having a little game, or just being silly, or didn’t want to be bothered bringing the lunch down. The more people go to the dining room the less work for them.” (Daughter of resident:CH30)

Privacy

This theme was defined as exclusion from the presence or view of others. Since limitations on privacy can interfere with the ability to maintain control, this theme is related to “independence, autonomy, choice and control.” Respecting residents’ personal space played a major role in maintaining privacy and therefore their dignity. This involved staff knocking on a resident’s door before entering and closing doors as well as windows and curtains when giving personal care. Residents’ bodies and bodily functions were shielded from view to protect their modesty.

“Well I would say that I can keep my things private — sort of. I can’t use the toilet, I have to use a commode in my room — because I have to use the hoist… They’ll always draw the curtains and shut the door, you know, and that is what I want. Privacy is your dignity really isn’t it? Well, I think if they weren’t careful on that side, or when you’re being washed… I mean they would never sort of put your stockings right, or anything like that, in the [ communal] room. They’d take you out into a toilet.” (80 year old woman living in CH9)

Occasionally staff spoke of the importance of residents having their own room, and respecting their private space and possessions. Their room was their home, and should be treated as such, with no one entering without a residents’ permission, unless such privacy was potentially dangerous.

“Although this building belongs to a company, it is their home, and we should treat it that way. When, when we go into a room, we knock on the door… and whatever they wish to do within that room, as long as it causes no danger to anyone else….” (Manager:CH27)

Less frequently, maintaining privacy and dignity involved confidentiality — not talking about personal or potentially embarrassing issues in front of others, or reading their personal letters. Privacy was related to choice and control when participants spoke of the importance of asking a resident’s permission to enter their room or involve others in their care.

Comfort and care

This theme was defined as actions contributing to the ease, wellbeing and contentment of residents. Participants in all groups felt that providing psychological and physical comfort and good

<table>
<thead>
<tr>
<th>Themes</th>
<th>Managers, n = 33</th>
<th>Care assistants, n = 29</th>
<th>Care home nurses, n = 18</th>
<th>Residents’ family, n = 16</th>
<th>Residents, n = 15</th>
<th>Community nurses, n = 10</th>
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<tr>
<td>Independence, autonomy, choice &amp; control</td>
<td>30 16 11 10 9 3 79</td>
<td>8 11 9 7 11 3 46</td>
<td>11 11 4 4 3 2 43</td>
<td>17 11 11 4 0 3 46</td>
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<td>27 12 11 6 4 2 24</td>
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quality care were important to help residents maintain a sense of dignity. This was the most prevalent theme for community nurses. Approaches to this included: giving love; touching; sitting and talking to residents; encouraging and supporting them; making them feel good about themselves; helping them feel peaceful; as well as attention to residents physical needs (such as keeping them clean and warm and free from pain, discrimination and abuse). The importance of being pain free was frequently mentioned by community nurses. Although we asked participants what could undermine a resident’s sense of dignity, no care home staff spoke of poor care in their home. However, one resident, two family members and one community nurse described loss of dignity as a result of poor care.

“...you make them feel comfortable — and “It’s alright — I mean you can’t do it but we can do it for you, that’s what we’re here for.” They like it... the touching... because they miss that you know.” (Care assistant:CH6)

“...to look out for their... if they have any pain. To be able to support them in that way and get the doctors to prescribe for more painkillers.” (Community nurse who visits CH14)

“...my bell, I rang the bell forty minutes — nobody answered it. I’ve had to go out and find them, and I never found them — there was nobody... I was promised that it would never happen again. The next day, the very next day, it was going for thirty minutes — I had to go out and find them... I could have been dead.” (64 year old man living in CH13)

**Individuality**

Individuality was defined as the particular character or group of qualities that distinguished one resident from another. This theme was related to “independence, autonomy, choice and control” when maintaining a resident’s individuality involved respecting their choices (e.g. food or clothing). Residents did not see dignity in terms of individuality, however, many care home staff and community nurses felt that, to foster a sense of dignity, it was important to see and treat residents as individuals including those with dementia. This involved appreciating their personalities and idiosyncrasies, and considering personal values and beliefs — particularly those of different cultures.

“...looking at their religion... ensuring that everything is put into place so that that person is respected... all their ethics and everything... That means to me, it’s very important, especially for someone who is dying. We can’t take away their belief, we can only learn, you know, and look at what that person’s beliefs are... If you have someone of a certain culture, just try to empathize, and do things so that their, you know, their dignity is not lost... When people are in a residential home they become as part of a family, and people get to know them. So knowing what the patient would like....” (Community nurse who visits CH26)

Where possible, residents should be allowed to live their lives as they used to. To achieve this staff felt that they needed to have time to get to know residents well. However, the son of one resident was critical of care assistants who failed to see residents as individuals.

“So there are some of them who don’t care [staff], but because I’ve been with them for such a long while... When you’ve been with that person for a certain time, you could know what she wants.” (Care assistant:CH14)

“...they [care assistants] don’t see what went before, and they don’t necessarily have a vision of the whole person. They just see an old person in front of them, and I think that’s part of the problem....” (Son of resident:CH30)

**Respect**

This theme was defined as the participant acknowledging a resident’s sense of worth and/or treating them with regard or consideration in the context of respect. Since all dignity promoting behaviors could be seen as respectful (e.g. respecting their privacy, choices, or individuality), text was only coded under this theme if the participant used the term ‘respect’. Participants in each group saw dignity in terms of respect. Some felt that residents “deserved” respect, or that it was due to them because of their age, or simply because they were human beings — even if they were no longer the person they were.

“...he is a man and he needs respect — as an adult, you know... Should have respect for your elders, and they should be treated with dignity and respect... I just wanted him to die with some kind of dignity, because everybody did look up to him and did respect him...” (Daughter of resident with dementia:CH13)

“...respect them... They are confused, but it doesn’t mean that they are like animals, or what. Still we have to respect them....” (Nurse:CH25)

Some participants simply said dignity was respect, self-respect, or being respectful. Others went on to describe ways in which respect could bolster a residents’ sense of dignity. Although staff acknowledged the importance of respect, one manager felt that staff were not always as respectful as they could be.

“Dignity is respect isn’t it? To be treated respectfully in their surroundings — in how you talk to them, or how you approach them.” (Care assistant:CH17)

“...giving respect is not as it should be, you’ve got to keep a firm hand on it... We carry out supervision with our staff six times a year, and generally we’re always talking about dignity, respect.” (Manager:CH29)

**Communication**

Communication was defined as the exchange of thoughts or information by speech. Although there are many other ways of communicating (e.g. body language, or touch), only spoken communication was coded here. Communication is related to autonomy when care-givers try to elicit a resident’s preferences or to persuade them, to privacy when they seek permission from residents, and to respect when communication style acknowledges a resident’s self-worth. Care providers felt that good communication was important, even when residents themselves were unable to communicate. Some staff felt that sensitively explaining what they were doing and why it was necessary, could help overcome a resident’s embarrassment or prevent them from becoming angry. Strategies thought to help included: speaking “gently” and politely; reassurance; listening to and acknowledging concerns; distraction and humor. Good communication could calm difficult or aggressive residents, and enable staff to persuade residents to accept their way of thinking. Although persuasion could result in a loss of independence or choice for residents, this was usually seen as necessary to provide good care, and therefore necessary for a resident’s own good.

One resident and four members of residents’ families gave examples of poor communication which could impact on a resident’s dignity.

“...so we never talk down to them or anything. We try to explain as much as we can and even though we have a high dependency level with dementia and... Alzheimer’s — but still you try to break the barrier... And have time, time you know. You can’t just run away from it, you have to sit there and listen. So listening is so important... However gobbledygook it is, it is still something.” (Care assistant:CH17)

“[member of staff] here argued with me — and I proved myself right. Afterward she’s got the tablet, she said “I bet you’re not in pain. Here’s your tablet. I hope they choke you to death.” Even if I was in the wrong, she’s got no right to talk to me like that. She sees me still — and it hurts...” (64 year old man living in CH13)

“If you speak to them to maybe in a not a respectful way or not a kindly way... keeping their dignity in everything, what they say,
what they do, how you treat them... This girl [staff], she kept on and on at [resident] ... and I mean shouting... I said, “Excuse me, I cannot listen to this any longer,” I said, “It’s disgraceful the way you’re speaking to [resident]” ... I mean respect and dignity and how, you speak to a person... And I think that more that, I have seen ... this attitude coming out in staff — and to say “how dare you speak to that resident like that.” I’ve seen it.” (close friend of resident:CH09)

**Physical appearance**

This theme was defined as maintaining outward or visible impressions of wellbeing or normality. Participants in all groups felt that maintaining dignity was about maintaining outward appearances — making them ‘look right.’ Being appropriately dressed was a way of helping residents to maintain their sense of self and individuality, and providing comfort and care could involve keeping them clean. However, this could be difficult for residents with dementia, who would sometimes undress themselves, or dress themselves inappropriately.

“Like if a patient, a resident is wet ... or open bowels when they are sitting — can start smelling and others will make comment. If they are not dressed properly ... you know some of them will just put a dress and get out, so we need to make sure they are done the right way....” (Nurse:CH30)

Here the need to look dignified could conflict choice and control, and staff shortages could make it difficult to keep up physical appearances. The daughter of a resident with dementia felt that staff were sometimes less than vigilant when it came to her mother’s personal care, and one community nurse felt that carers sometimes ignored serious problems such as distress as long as residents were clean.

“... there’s times I’ve been there where she smells like she hasn’t had a wash, and I’ve had to go in there and give her a wash or a shower... I’d go in there and she had no knickers on. You know, and I was like ah, there’s no reason for any of that to happen as far as I’m concerned... I know like they’re short of staff at the home anyway, and I know they can’t check, they check them all, all the time — but just be a bit more vigilant and things like that.” (Daughter of resident with dementia:CH31)

“Some of them [residents] will be crying or moaning or... But this one is clean... It’s really addressing what it’s really about. It’s just about the carer who doesn’t really know how to observe for any complication or any — if there’s a problem.” (Community nurse visiting CH17)

**Being seen as human**

The focus of this theme was on treating a resident as a normal person — a thinking, feeling being rather than just a number or a job to be done (e.g. another object to be cleaned or moved). However, in contrast to individuality, which emphasizes distinct character or personality, the resident could be any human being. Being treated as a normal human being was particularly important for residents with dementia. One resident (who did not have cognitive problems) described her frustration at being treated as someone without a brain.

“A lot of them have a lot of mental disability, because they have brain trauma. Dignity for them is being treated as a normal person, not being patronized.” (Manager:CH05)

“When it comes to the actually going in the treatment room, they spoke to her [carer], and I was annoyed about that. I said, “Don’t you dare speak to her about it,” I said “It’s me. I’ve got a brain and I can talk for me self.” (84 year old woman living in CH28)

**Discussion**

This study includes a range of perspectives on the maintenance of dignity in care homes, showing that overall, participants felt that maintaining independence, autonomy, choice and control and privacy were important factors in maintaining dignity for residents. Providing comfort and care, seeing residents as individuals, respect, good communication, maintaining resident’s physical appearance, and treating them as human beings were also seen as important. Community nurses focused more on providing comfort and care than fostering independence, autonomy, choice and control. In contrast to care providers, residents and their families described incidents where a resident’s dignity had been compromised. Although care providers acknowledged the importance of fostering a sense of dignity, they felt that the need to protect residents could limit their sense of freedom, choice and privacy, and therefore their dignity.

Although some themes, such as independence, autonomy, choice and control and privacy resonate with those found in several earlier studies, less frequently reported themes such as the importance of providing comfort and care, good communication, maintaining physical appearance, and being treated as human emerged in our study. This may have been due to the range of different perspectives in our study, and the nature of the care provided in care homes — usually long term and for frail people, often suffering from dementia. Participants often viewed dignity and good care as equally important. Similar themes emerged in the Dignity and Older Europeans study (e.g. maintaining personal appearances and being treated as human), which also included a range of different perspectives (care home residents and care providers).

We found considerable similarity between the views of different care providers and residents and their families, however, there were also differences. Community nurses may have rarely spoken of independence, autonomy, choice and control in the context of dignity, possibly because their role focused more on medical care than the day-to-day life of residents. Residents seemed more concerned with the physical aspects of maintaining dignity such as independence and comfort and care, rather than being treated as human or as individuals. This may have been because the latter is particularly important for residents with dementia, and none of the residents who took part in our study were suffering from dementia.

The most striking difference is that, in contrast to residents and their families, care home staff rarely described incidents where they felt that residents had been given poor care or their dignity had been violated. We can only speculate as to why this was the case, possibly because these incidents were more salient to residents and their families, or because care home staff were unwilling to report such events. However, it is reassuring to see that care providers seemed aware of ways to foster residents’ dignity, although there was suggestion that such knowledge was not always put into practice. Efficiency and production are important in most care homes and time constraints and heavy workload can be barriers to providing dignity conserving care. Staff often need to prioritize and regulatory emphasis tends to be focused on markers of poor physical care and safety. Care home staff may face ethical dilemmas when their working environment is not conducive to providing dignity conserving care.

Maintaining dignity for residents with dementia presented particular challenges for care providers. A resident’s capacity can vary, and it is a challenge for care providers to decide when a resident is capable of making autonomous decisions, and the need to balance their wishes with a need to minimize risk presents another dilemma. As a result of our increasingly litigious society, staff are likely to be encouraged to restrict residents’ activities to reduce risk. There have, however, been questions about who is being safeguarded — the residents or the home owners, and there is a need to contextualize safety with due regard to residents’ right to
autonomy and their dignity.20 Most residents need assistance with activities of daily living, which often leads to paternalism, beneficially meant, but still harmful to residents’ autonomy.21,22 In a care home setting, the clash between paternalism and autonomy often occurs in everyday occurrences (e.g. freedom of movement, choice of food, what to wear, bathing etc.). In these situations, staff used their communication skills as tools of persuasion. This could be done to protect a resident without causing them distress, or sometimes simply to make life easier for staff, who are usually in a position to decide if a resident is capable, and whether their wishes are safe and reasonable. Dignity violation is likely to occur when one actor has more power, authority or strength than the other.23

The tension between the rhetoric of dignity conserving care and the reality experienced by residents and their families is one of those described by Jacobson in relation to dignity violation in health care – “the multiple disjunctions between stated policy and what actually occurs.”23(p1544)

Limitations

A methodological strength of our study is the inclusion of care providers, residents and their families, giving us the opportunity to compare perspectives. The main limitation is the use of probability and convenience rather than purposeful samples. This limits the generalizability of our findings. As the participants were identified by care home managers, the sample may not have represented the views of all residents in the care home, as those residents who managed perceived to be more likely to be critical of their care provision may have been less likely to be sampled. It is possible that more themes have emerged and additional comparisons made with purposeful samples. It would have been useful to, for example, explore cultural differences. The low response rates for some of the participant groups are also a limitation of the study, as a greater number in each group would have given us more breadth to their views of maintaining dignity.

Conclusions

Issues of dignity are embedded in the everyday interactions between residents and care providers. Treating residents with respect, promoting their independence, autonomy, choice and control whilst minimizing risk, and ensuring their privacy helps residents of care homes maintain dignity. Focusing on fostering dignity can be a starting point for improving the quality of care and quality of life of residents. However, it is important to remove the gap between the rhetoric of dignity conserving care and the reality experienced by residents in these and in other care settings. This could be achieved by providing care homes with sufficient resources along with quality assurance programs, which provide leadership, support and training and training for staff.

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References