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Ethical challenges associated with providing continence care in residential aged care facilities: Findings from a grounded theory study

Abstract

A person-centred approach to care in residential aged care facilities should uphold residents' rights to independence, choice, decision-making, participation, and control over their lifestyle. Little is known about how nurses and personal care assistants working in these facilities uphold these ideals when helping residents to maintain continence and manage incontinence. The overall aim of the study was to develop a grounded theory to describe and explain how Australian residents of aged care facilities have their continence care needs determined, delivered and communicated. This paper presents and discusses a subset of the findings about the ethical challenges nurses and personal care assistants encountered while providing continence care. Grounded theory methodology was used for in-depth interviews with 18 nurses and personal care assistants who had experience of providing, supervising or assessing continence care in an Australian residential aged care facility, and to analyse 88 hours of field observations in two facilities. Data generation and analysis occurred simultaneously using open coding, theoretical coding, and selective coding, until data were saturated. While addressing the day-to-day needs of residents who needed help to maintain continence and/or manage incontinence, nurses and personal care assistants struggled to enable residents to exercise choice and autonomy. The main factor that contributed to this problem was the fact that nurses and personal care assistants had to respond to multiple, competing and conflicting expectations about residents' care needs. This situation was compounded by workforce constraints, inadequate information about residents' care needs, and an unpredictable work environment. Providing continence care accentuated the ethical tensions associated with caregiving. Nurses and personal care assistant responses were mainly characterised by highly protective behaviours towards residents. Underlying structural factors that hinder high-quality continence care to residents of aged care facilities should be urgently addressed.

Keywords: Incontinence, aged care, ethics, autonomy, choice, independence, nursing home

Background

The quality of care in Australian residential aged care facilities (RACFs) is partially evaluated on the basis of residents' involvement and satisfaction with care, and this evaluation is overseen by the

Joan Ostaszkiewicz*
School of Nursing and Midwifery, Deakin University, Burwood, VIC, Australia
Email: joan.ostaszkiewicz@deakin.edu.au

Beverly O'Connell
Dean of Faculty of Nursing, Manitoba University, Winnipeg, Canada

Trisha Dunning
Chair in Nursing, Deakin University — Barwon Health, Geelong, VIC, Australia

*Corresponding author

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Australasian Aged Care Quality Agency (AACQA), formerly the Aged Care Standards and Accreditation Agency Ltd (ACSAA). The AACQA assesses RACFs' performance against four Aged Care Accreditation Standards and 44 expected outcomes. The expected outcome of Accreditation Standard 3.9 (Resident Lifestyle) is "residents have the right to independence, choice, decision-making, participation and control over their lifestyle that does not infringe on the rights of others". These rights are enshrined in the Aged Care Act1 and are further articulated in the Charter of Residents Rights and Responsibilities2. Aged care policy and industry advertisements promote hotel-like services and promise residents' choice and autonomy. The Australian Human Rights Commission3 champions residents' choice and promotes resident-centred decision-making.

Health care professionals' codes of conduct, ethics and competency standards also uphold the rights of a resident to make choices. The Code of Ethics for Nurses in Australia requires nurses to respect the rights of persons to make informed choices about their care4. Despite the emphasis on residents' independence, choice, decision-making, participation and control, there is very little published research about how
nurses and personal care assistants (PCAs) working in RACFs enact such rights, particularly when caring for residents who require high levels of assistance, including assistance to maintain continence or manage incontinence.

According to a 2011 report, 71% of residents in Australian RACFs are incontinent of urine or faeces or both, and of those residents, 54% experience more than three episodes of urinary incontinence a day and 34% experience more than four episodes of faecal incontinence per week. A large proportion, 68%, are dependent on nurses and PCAs for assistance to use the toilet and would be incontinent if they did not receive assistance. It is also probable that many residents experience other bladder and bowel symptoms and conditions, such as constipation, faecal impaction, urinary urgency and frequency, urinary tract infections (UTIs), and nocturia.

Despite the high prevalence of incontinence among residents of RACFs and the need for assistance to maintain continence and manage incontinence, there is little contemporary research about the practical and ethical day-to-day issues about caring for such residents.

Aim and objectives

The overall aim of the study was to develop a grounded theory to describe and explain how residents of RACFs in Australia have their continence care needs determined, delivered, and communicated. The objectives were to: (i) explore and describe nurses’ and PCAs’ perspectives about providing, assessing, or supervising residents’ continence care needs, including barriers and facilitators to such care, (ii) their beliefs about incontinence and continence care; and (iii) to describe, through field observations, how they recognize and respond to residents’ continence care needs in public areas of the RACF. This paper presents and discusses a subset of the findings related to the ethical challenges nurses and PCAs encountered.

Method

The study was conducted using grounded theory methods as described by Glaser and Strauss4 and Glaser5. The method included theoretical sampling, constant comparative data analysis, theoretical sensitivity, memo writing, identification of a core category, and theoretical saturation. Data were derived from formal, semi-structured, open-ended and in-depth interviews with RACF staff and from field observations of practice in two RACFs.

Sample and setting

Formal, semi-structured, open-ended and in-depth interviews

Eighteen care staff — experienced in providing, supervising or assessing continence care in an Australian RACF — participated in formal, semi-structured, open-ended, in-depth interviews. Six were registered nurses (RNs), six were enrolled nurses (ENs) and six were PCAs. Four of the RNs worked as Directors of Nursing and two were Clinical Nurse Educators. Five of the six RNs had post-graduate qualifications. One of the ENs and two of the PCAs were concurrently enrolled in an undergraduate nursing degree program.

Nurses and PCAs who volunteered to be interviewed did so after hearing about the research. At a professional network forum for nurses, from a colleague who had participated in the study, or at an information session for undergraduate nursing students at a tertiary education facility.

Consistent with grounded theory methods6, the nature of the interview questions and the sampling frame arose from the emerging analysis and was determined according to what was learned from previous data sources.

Non-participant field observations

Eighty-eight hours of non-participant field observations were conducted in two purposely selected RACFs: a 75-bed not-for-profit RACF in Melbourne, Victoria, and a private, 50-bed RACF in Adelaide, South Australia. The observational periods encompassed four eight-hour morning shifts (32 hours), four eight-hour afternoon shifts (32 hours), and three eight-hour night duty shifts (24 hours). The sites were purposely selected on the basis of having a mix of RN, EN and PCA staff, a large number of highly dependent residents, and a resident population that included, but was not limited to, individuals with dementia.

During observation periods, routines of care and interactions between staff and residents were observed from a discreet distance from staff–resident activity and in shared areas of each facility. Information sessions were convened at each site to ensure open disclosure about the study and organisational consent was provided for the researchers’ presence. During observations, the researcher regularly checked to ensure staff and residents were comfortable with her presence in the area of the facility. The researcher wrote occasional field notes about the work staff performed and the way they recognised and responded to residents’ care needs. The observational data were later followed up with the interview participants. From these observations, certain taken-for-granted aspects of practice were identified and prompted further inquiry.

Analysis

All data were entered and managed in QSR International NVivo 9 software program (QSR International Pty Ltd 2010). The data were analysed using open coding, theoretical coding, and selective coding techniques. The coding occurred at the same
time as data generation and analysis. The researcher assigned one or more codes or labels to the text to describe what the data indicated. Simultaneously, memos were constructed about the emerging ideas from the coded data. All stages of coding involved comparing code-to-code, incident-to-incident, category-to-category to establish underlying uniformity and to ensure the data fitted until higher order concepts emerged and a basic social problem and a basic social process were revealed.

Results

The findings of the main study resulted in a theory about how overall care, including continence care was delivered in RACFs. The theory comprised 1) a basic social problem termed ‘caring against the odds’, which described the main problem RACF staff experienced whilst performing their work; and 2) a basic social process termed ‘weathering constraints’, which explained how these staff grappled with, or responded to this problem.

‘Caring against the odds’ was characterised by multiple constraints to care. The four subcategories that emerged from the data analysis as having most impact on staffs’ ability to perform their role and deliver care were: (1) the experience of working in a highly regulated work environment; (2) encountering ethically challenging situations; (3) resident’s high levels of dependence, and (4) a devalued role. ‘Weathering constraints’ explains how staff responded to the constraints to care. It offers a theoretical explanation that accommodates the personal, social, organisational and regulatory factors that influenced overall care. The process was characterised by two sub-processes: 1) attempting to accommodate the context of care, and 2) adopting self-protective distancing strategies.

Encountering ethically challenging situations

Participants in the study espoused residents’ rights to autonomy, independence and self-determination, including their right to make decisions about what care they wanted and when they wanted it. They claimed residents had the right to be treated as if they were in their own home. However, the findings of this study show that while participants state that they know about residents’ rights to choice and autonomy, this is discordant with their ability to fulfill their obligations and to operationalise the rights they espouse. There were a number of interrelated or contextual factors that collectively caused staff to experience ethical challenges whilst performing their work. The researcher grouped these factors as follows:

- Multiple, competing and conflicting expectations about residents’ care needs.
- Workforce constraints.
- Inadequate information about residents’ care needs.
- An unpredictable work environment (Figure 1).

Multiple, competing and conflicting expectations about residents’ care needs

An interpretation of the collective data suggested the main reason participants found it difficult to work in a manner to uphold residents’ rights was because they needed to grapple with multiple, competing and conflicting expectations about residents’ care needs, which the researcher interpreted as a competing duty of care.

The main expectation influencing the overall delivery of care was that residents had to appear to be clean and well groomed. Participants generally all expressed they had to prioritise resident cleanliness and appearance over other aspects of care. This implicit expectation was related to ‘social, taken-for-granted values and expectations’ linking incontinence with uncleanliness and indignity. When participants were asked why they spent most of their time washing residents, one participant stated: “... we have to keep their dignity” (Int-04).

Participants stated that they would violate their own and colleagues’ norms about care if residents were unclean from urine or faeces. There was criticism of colleagues who did not check and change residents’ pads when residents were significantly wet or soiled.

Incontinence, urinary or faecal, was a major symbolic and physical threat to residents’ cleanliness and had a significant influence on how participants spent their time and structured their day. Residents voided and were incontinent several times over a 24-hour period and each care episode could potentially be complicated and lengthy. However, participants revealed a pragmatic way to manage the situation that involved promoting residents’ use of pads, and reframing their own understanding about what was ‘clean’ and what was ‘dirty’, so that certain
levels and types of incontinence were tolerated. This tolerance varied, depending on the volume of a resident’s incontinence, whether their incontinence was visible or not, and the type of incontinence. Specifically, residents whose pads were soaked or soiled with faeces were considered ‘duty’. Such residents were washed. By contrast, a resident with a small volume of urinary incontinence that was contained within a pad was considered ‘clean’. They had their pad changed, but were not routinely washed.

Not only did participants express that they felt compelled to ensure residents appeared clean; they also felt compelled to complete residents’ personal care regimen, cleanliness and social appearance, before an arbitrary predetermined time, usually before lunchtime and, in some cases, before breakfast. However, the work involved in keeping residents clean was highly labour-intensive, unremitting, and consumed the majority of the shift, particularly on a morning shift.

After attending to each resident’s personal care needs, participants had little time to address any other care needs. Participants expressed their considerable frustration in their roles as they were limited in what they could achieve and not always able to reconcile their competing duty of care to provide each resident with individualised care, while attending to the needs of many residents. For example, while a participant assisted one resident to shower, they were not in a position to also meet the needs of other residents. A participant articulated the dilemma as follows

“You might be doing [assisting a resident to shower or bathe] one person and you know that another person is dying to go to the toilet but you can’t leave that person” (Int-10).

In such compromised situations participants had to prioritise between helping an individual resident to be safe in the shower and another resident’s need for help to maintain continence. Both residents were at risk of falling.

Another situation that represented an ethical dilemma for participants was when residents did not believe they needed assistance to walk to the toilet. Many residents, including some with the diagnosis of dementia, often relied against such dependence on staff. Staff and residents often differed in their opinions about the risk associated with a resident’s attempts to exercise such independence and autonomy, which caused considerable frustration for staff. For example, participants indicated they were upset by their inability to prevent some residents from attempting to walk to the toilet alone, and from sustaining a fall or injury. A participant described the dilemma as follows:

“We have one that... she used to get up and walk and try to do everything by herself. And I said, ‘I didn’t like the idea of her walking because you still needed someone to adjust your clothes when you go to the toilet, to adjust your clothes when you get off the toilet, you only have one hand.’ But she insisted. She wanted to do things when she wanted to do them. My fear was she [sic] going to be off balance, fall down and break her hip. She did this. She can’t get up now” (Int-09).

Workforce constraints

The researcher theorises the ethical challenges participants encountered in their roles were compounded by workforce constraints such as low staffing levels, few RNs, and staff with minimal educational preparation and English proficiency. Participants described having to rush care and adopt efficiencies that meant they could not spend sufficient time with each resident to meet their basic care needs. For example, participants stated finding time to assist residents to go to the toilet or change their pads when needed was a real challenge in the context of current staffing levels. The situation was allegedly worse at night when some participants rationalised the absence of toileting assistance on the basis of the lower ratio of staff to residents at night than during the day.

Low staffing levels, a limited number of RNs, and staff with inadequate knowledge and skill also led to ethically compromised care. Participants stated they were not always able to find a colleague to assist them to perform their roles and RNs were not always physically present at facilities, causing participants to express they felt alone and unsupported. One participant articulated the challenges of working in an environment characterised by workforce constraints as follows:

“It’s very constrained and there is not enough time or enough people to do the work you want to do. They say its holistic care in aged care but you really don’t have the time.” (Int-06).

Inadequate information about residents’ care needs

Another factor that contributed to the ethically challenging nature of the care environment was that staff did not always know the residents or their care needs. This situation was exacerbated by an inadequate number of staff to provide care, use of agency staff, a lack of RNs, and changes to RNs’ roles that increased their managerial responsibilities and reduced their involvement in direct care activities. In addition, the starting times of shifts were often staggered and up-to-date information about residents and their care needs was not always available. A further complicating factor was that information about residents’ care needs, routines and behavioural cues were not always documented. Not knowing individual residents’ needs or preferences was particularly difficult for new or temporary staff and students who relied on care plans being available and up-to-date. When participants were asked how they learned to identify residents’ individual behavioural cues, one said
"You don’t know — it’s not written down. It’s hands on. You pass it down to the new staff. It’s never official. [If you are a new staff member] that’s where it’s hard. You don’t know if you have a nice stuff on that will spend half an hour with you at the start of the shift, you can tell them." (Int-06).

An unpredictable work environment
An additional factor that contributed to the ethically challenging nature of the work environment was that staff lacked control over their day-to-day work. From field observations it was revealed that participants were frequently interrupted throughout the course of their day by unplanned issues. These unplanned issues included (i) resident falls, (ii) acute illness or deteriorating health status of a resident that sometimes led to challenging behaviours, (iii) a resident’s death, (iv) outbreaks of gastroenteritis, (v) human resource issues such as staff with inadequate knowledge and skills, staff injuries, staff shortages, new or agency staff, changes to or new policies and procedures, (vi) residents’ family members needing support; (vii) visits from doctors, consultants, assessors from the ACSAA, or officers from the Office of Aged Care Quality and Compliance; and (viii) complaints from residents or family members. Another situation over which staff had little control was when residents’ incontinence was uncontrollable.

One participant, a PCA, described the difficulty controlling or predicting work flow in a dementia care unit, where anything could happen including situations in which staff were confronted with; ‘shit everywhere’ causing them to have to stop what they were doing and clean it up. She said:

"Every day something different happens. You can’t say it is 3 o’clock and I’ll do this now. You can’t do it because sometimes they [residents in the dementia unit] are in a good mood and sometimes they are not and sometimes you find shit everywhere. Every day is different." (Int-01).

As unplanned issues could occur at any time and divert staff from addressing residents’ care needs, participants worried about having to reprioritise their work or being unable to perform their role, and hence they operated under the constant expectation of an impending crisis.

Protecting residents
Participant responses to ethically challenging situations they encountered were mainly characterised by highly protective

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behaviours towards residents. One reason participants adopted a highly protective response was because they were afraid that adverse events could prompt an investigation by the ACSAA. Protective behaviours ranged from the use of skilled, therapeutic communication techniques, to strategies that caused or exacerbated a resident's distress.

**Highly skilled communication techniques**

Skilled, therapeutic communication strategies included: using touch in an appropriate manner, making eye contact, speaking in low tones, offering residents choices, using encouraging language and humour. Participants spoke about ways of interacting with individual residents that would enable them to assist that resident with personal care activities such as going to the toilet, showering or bathing, and changing pads. A PCA with many years of experience described how she interacted with a resident to encourage him to accept her help to be clean after an episode of incontinence, and to wear a pad. She said:

“Slowly, slowly, talking to him — not telling him. ’It’s okay, love, we [sic] going to clean up after you.’ But there’s a way to talk to him — ’Look we all have an accident — what we do is we change this and we keep this on for you — for your own protection — you can still go to the toilet.’ And he feels good and he starts going out again and joining in the activities.” (Int-04)

**Conditioning strategies**

Other participants described techniques such as frequent reminders or prompts, repetition, guise and the use of normalising strategies. For example, residents may be often reminded they needed to call for help to use the toilet because of the risk of falling if they attempted to walk to the toilet alone, or they needed to wear and use pads because were not able to maintain continence. When asked how residents’ ultimately accepted wearing pads, a manager stated:

“I think they [staff] spend time telling the resident just why it’s [a pad] important. That it’s there and it’s for their comfort. Not for anything else. And other people are using it and it’s not just you. It’s quite difficult, when they have cognitive impairment. So it’s time and repetition and eventually I think they [residents] probably get it worn down.” (Int-07).

Repetition and reminders were also used to ‘protect’ residents who were cognitively impaired, albeit with limited efficacy. A PCA who stated she was in charge of a dementia-specific unit said:

“So you explain why you give it [a pad] to them [residents]. [Staff say] ’You [the resident] are not going to the toilet by yourself. You are going too late.’ You have a chat with them, and five minutes later they have forgotten what you said to them so they have taken it [the pad] off and you notice that they have taken them off and then you tell the whole story again [laughter].” (Int-01)

Another conditioning strategy involved gradually introducing pads to residents or using guise, applying continence aids that resembled underwear. The underlying intent was to assist the resident to adjust to wearing a pad. Once the resident accepted wearing a small pad or a pad that felt like normal pants, staff gradually increased the pad size or type to better accommodate the frequency and volume of the resident’s incontinence episodes.

Conditioning strategies were accompanied by normalising processes. For example, participants would tell residents that incontinence was normal for their age or medical condition, that most women who had borne children were incontinent, and incontinence happened to everyone. Participants would also tell residents they were used to dealing with incontinence and it was a ‘normal’ part of their job. Normalising incontinence and pad use were strategies designed to protect residents from embarrassment and help residents accept wearing and using incontinence aids.

**Strategies that caused and/or exacerbated residents’ distress**

On the basis of the need to ‘protect’ residents when providing care, particularly continence care, some strategies described by participants caused and/or exacerbated residents’ distress. For example, a staff member’s response to a cognitively impaired resident’s incontinence episode involved confronting her with the incontinence, arguing with her, chastising her, reminding her of her inability to know what she is doing, and then instructing her to call for help next time. One participant said:

“We had [sic] a resident, she did doing it [incontinence] everywhere and I said, ‘Oh no, not again, well, what did you do?’ But they have dementia and when I ask, ‘Do you know what a toilet is?’ And she says, ‘Of course I know what a toilet is’. ‘OK, but you did it on the floor.’ ‘I didn’t do it.’ She did it. Because the first thing is … I didn’t do it, another lady did it.’ I said, ‘Sorry, it’s your pants, it’s your underwear, you are wet.’ And they say, ‘Oh, oh yes. I am so sorry I am so sorry. I am so sorry.’ And I say, ‘No, no, it’s OK, you don’t know… it’s an accident. Come on, I’ll fix you up and now don’t be sorry. It’s my job. I don’t care. But I have to tell you, tell me if you need to go to the toilet, push your buzzer and I push you to the toilet so that we can be on time so that you are not wet.’” (Int-01).

Discordant beliefs about the level of risk associated with residents’ attempts to exercise independence also set the scene for highly charged emotions, and at times led to a situation in which both parties struggled for control. Staff efforts to control and contain a resident’s incontinence (or assumed incontinence) could cause considerable conflict. Indeed, providing continence...
Providing continence care necessarily involves invading a person's body boundary and personal space. It should, therefore, be recognised as a common antecedent for a resident's distress response, and staff should be empowered with the knowledge and skill to not only manage a resident's responses, but, more importantly, prevent the situation from escalating into a struggle for power and control. In the current study, some staff interpreted a resident's attempts to remove, hide, and wash and reuse their disposable pads as resisting care, rather than as a response to shame and fear about being humiliated for being incontinent. Indeed, Robinson's grounded theory study about the cognitive, psychosocial and behavioural aspects of living with urinary incontinence in nursing homes found residents' attempts to conceal incontinence were due in part to a fear of being alienated by staff and represented a cognitive effort to preserve dignity and protect one's social integrity. As such, residents' responses to incontinence mirror those of people living in the broader community wherein fear of humiliation causes both women and men with long-term incontinence to conceal their condition and deters them from seeking advice. Arguably, education programmes need to prepare RACF staff with the knowledge and skill to interpret and respond sensitively to residents' emotional responses to incontinence.

Participant responses to residents' incontinence varied. Some described practices that involved applying considerable pressure on residents to adhere to their advice, particularly their advice to wear pads. Kitwood described such responses and practices as, "... as such forms of deception, treachery, disempowerment and infantilisation", and claimed they were a form of malignant social psychology used to manipulate or gain control over a person, and that they did not honour the dignity and personhood of the care recipient. At the same time, he acknowledged that caregivers did not intend to be malicious but adopted these strategies because they were overwhelmed by the "demands of the disease" and lacked sufficient support. In the current study, use of guise was underpinned by participants' definition of duty of care or desire to protect residents. This finding is consistent with the findings of a qualitative study of people living with Alzheimer's disease in the community which found, "... family caregivers used techniques of deception but mostly in situations where it was necessary to protect the safety and wellbeing of their family member".

Shaming was another coercive strategy some staff inadvertently used. Similarly, relations between staff and residents concerning continence care were sometimes adversarial and characterised by what appeared to be, a struggle for power and control. From an anthropological perspective, shame or guilt are used to regulate the social activities of individuals and thus may
be seen as a form of social control\textsuperscript{15}. The unethical use of power in a caregiving or institutional context is not without precedent Oliver\textsuperscript{16} stated, “Several empirical studies from an institutional perspective have noted that struggles for power and control often underlie institutional processes” There are multiple interpretations about the use of physical force in the context of a caregiving relationship For example, a Foucauldian interpretation posits that, “in order to be successful, caregivers must establish a relationship of power over care recipients in which they substitute their judgement and actions for those of their family members”\textsuperscript{111}. The indefensible benefit for staff of dealing with a compliant resident was that staff members were better placed to minimise residents’ risks of falling, contain their incontinence, and keep them in a clean state Foucault's critical interpretive analysis may go some way to explaining how it is that residents ultimately accept wearing pads even when they were continent.

However, at the heart of staff behavioural responses was a set of conditions that set the scene for unethical care. These problems included, but were not limited to workforce constraints. In Australia, Beth Wilson, the former Health Services Commissioner for Victoria\textsuperscript{17} championed the rights of people living in RACFs to access to what she termed “dignified continence care” as a human right. She called for additional staff in order to offer residents “high quality, appropriate and dignified aged-care services”. If individuals living in RACFs are acknowledged as full citizens, there is a need to question the ethics and the human rights issues of resourcing facilities at levels that hinder staff from providing residents with basic care such as toileting assistance.

**Conclusion**

Although residents have the right to independence, choice, decision-making, participation and control over their lifestyle, the findings from this study revealed multiple structural factors that hinder staff from fully exercising this right and from meeting residents’ basic human need for support. Further attention should be given to the concerns of staff about the difficulties experienced providing residents with the quality of care they deserve. In its effort to reform the quality framework that underpins the Australian residential aged care sector, it is incumbent on government to address the underlying structural factors that hinder staff from delivering high-quality continence care to our older citizens.

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