Learning to accept incontinence and continence care in residential aged care facilities: Family members' experiences

ABSTRACT
The psychological process of living in a residential aged care (RAC) facility and being incontinent and dependent on another person for assistance with bladder and bowel function is largely uncharted. Likewise, little is known about the experiences and opinions of next-of-kin family members. As the function of many family members is as key advocate for residents, it is important to understand and share their perspectives about quality continence care. The aim was to explore next-of-kin family members' understandings and expectations about the concept of 'quality continence care' for their relative living in an RAC facility. The findings suggest shared indicators of quality continence care centre on practices that family members believe will maintain a resident's cleanliness and comfort, interpret the behaviours of cognitively impaired residents, optimise personal continence and autonomy, identify and address underlying medical conditions, and validate family member roles as advocates. The findings led to the development of a typology of family member beliefs and expectations about quality continence care, which could inform the development of future education programs for the aged care workforce, as well as the development and implementation of a best practice guideline for quality continence care in RAC facilities. By providing important insights into family members' understandings and expectations about continence care, the research contributes to international efforts to improve the quality of continence care for frail older adults.

Keywords: Incontinence, quality of care, quality indicators, residential aged care facility, family.

INTRODUCTION
Admission to a residential aged care (RAC) facility should not end a person's relationship with their family. Indeed, many family members maintain ongoing contact and some are very involved in decisions about various aspects of a resident's care. Although there is an emerging body of knowledge about experiences and involvement of family members in a resident's general care, dementia care, and end-of-life care, little is known about family members' experiences and involvement in residents' continence care.

The term 'continence care' refers to the range of activities carers perform to assist care-dependent individuals to use their bladder and bowel and to maintain continence and manage incontinence. Data about the prevalence of incontinence and care dependence in Australian RAC facilities suggest most residents require high levels of assistance with bladder and bowel function and toileting; up to 71% of RAC residents are incontinent of urine (UI), faeces

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ability to self-manage activities of daily living (ADLs) and to compensate for their impairment, and to manage incontinence. Another important consideration is the challenge of managing incontinence and optimising continence in the context of the high rates of cognitive impairment; in some cases, managing incontinence and/or promoting continence is complicated by behaviours such as faecal smearing.

Although multiple factors are implicated in the aetiology of incontinence in frail older adults, and many people admitted to RAC facilities have pre-existing incontinence, functional causes predominate; specifically, impaired mobility, which increases the risk of UI by 80%. The International Consultation on Incontinence (ICI) defines functional UI as “the complaint of involuntary loss of urine that results from an inability to reach the toilet due to cognitive, functional, or mobility impairments in the presence of an intact lower urinary tract system” (p. 364). People with functional UI (whose UI is caused by a cognitive, functional, or mobility deficit), will be incontinent in the absence of toileting assistance.

There is a large body of research showing toileting assistance programmes are effective in reducing rates of UI in people living in RAC facilities, particularly when they are combined with exercise interventions to maintain or improve a person’s functional abilities. Indeed, improvements are noted shortly after the intervention is implemented; however, they usually return to baseline levels under usual care conditions.

In the only analysis of the cost and labour associated with implementing a systematic toileting assistance programme in RAC facilities, Schnelle and colleagues reported that staffing resources required to provide residents with assistance to use the toilet at levels that reduce rates of UI, far exceeded the staffing levels of most facilities. Thus, there are difficulties in translating the findings of research about the beneficial effects of exercise and toileting assistance programmes into practice in RAC.

There is very limited research about family members’ beliefs about the perceived benefit of toileting assistance programmes or any other type of intervention that could potentially prevent, minimise or treat incontinence in RAC facilities. One report is based on a descriptive, comparative survey from groups likely to serve as proxy decision makers for residents, that is (171/403) family members, 66 nursing staff, and 79 older adult residents from facilities in the USA. Respondents were asked to rank their preference on an 11-point visual analogue scale for ‘diapers’ (absorbent pads), ‘prompted voiding’ (PV) [a toileting assistance programme], ‘indwelling urinary catheterisation’ (IDC), ‘electrical stimulation’ (ES) and ‘medication’. While most respondents preferred non-invasive strategies (diapers and PV) to invasive strategies (IDC and ES), several family members and older adults considered PV to be “embarrassing” and were concerned that it “fostered dependence.” This finding warrants further investigation.

Given the ability to maintain continence is a ‘taken-for-granted’ skill that is achieved in early childhood, society places considerable emphasis on independence and bladder and bowel control. There is a powerful stigma attached to the loss of bladder and/or bowel control and it is probable there is a profound, but largely uncharted process of psychological adjustment to being incontinent, using pads, and being dependent on another person for assistance with bladder and bowel function. It is probable that family members who have a vested interest in a resident’s physical, emotional and social care are also affected by this process; however, their experiences and opinions are not known.

**AIM**

The aim of the study was to explore next-of-kin family member understandings and expectations about the concept of ‘quality continence care’ for their relative living in an RAC facility.

**METHODS**

The research was conducted as a naturalistic inquiry using a qualitative exploratory descriptive (QED) research approach. Naturalistic inquiry provided an ideal method to explore experiences and actions of participants, particularly as no relevant theoretical framework was available and little was known about the topic. It also offered a means by which to elicit important contextual information.
Sample
Consistent with the tenets of qualitative research, participants were purposively selected. Eligibility was extended to next-of-kin family members who had a relative living in an RAC facility anywhere in Australia. We aimed to recruit up to 20 participants.

Recruitment
Multiple recruitment methods were employed over 12 months, including a snowballing technique; selective placement of information in print and electronic media; and information sessions convened at a number of RAC facilities. People who volunteered to participate were interviewed by phone in an anonymous, one-off, confidential, audio-recorded, semi-structured interview with the researcher (JO). They were invited to share their beliefs, opinions, understandings, expectations, and experiences about ‘quality continence care’ in RAC facilities. Once recorded, the interviews were transcribed and securely stored as a computer file and de-identified in accordance with ethical guidelines for research.

Ethics
Ethical approval to conduct the research was obtained from the Human Research Ethics Committee at Deakin University prior to commencement of the study.

Analysis
Data were analysed using inductive content and thematic strategies to build constructions of ‘quality continence care’. Two researchers independently read short segments of the transcribed interview text data to closely examine, interpret, code, and categorise the text. A coding matrix was developed and codes were independently assigned to the text to describe the data. The codes and their content were repeatedly read, regrouped and recoded in order to delimit the overall number of codes and to ensure consistency and fit. Thereafter, independently coded data were compared and agreement reached. This inductive process ensured the findings were grounded in the data.

RESULTS
Five next-of-kin family members were interviewed. Their average age was 73 (range 64–82) (1 male: 4 female). Two family members were daughters of a resident, one was an elderly husband, one was an elderly wife, and one was a sister. In each case, the family member’s relative was cognitively impaired. Two participants were former registered nurses (RNs).

Family members’ responses to questions about continence care were characterised by the frequent use of the term ‘dignity’. Specifically, their opinions about ‘quality continence care’ were linked to beliefs about strategies or practices they believed would dignify their relative and that would make family members feel involved and validated as an important person in the relative’s life. Table 1 lists the strategies/practices, which we used to create a typology of family members’ beliefs about quality continence care. They include:

- Keeping residents clean and comfortable.
- Interpreting residents’ behaviour.
- Prompting and assisting residents to the toilet.
- Employing knowledgeable and skilled staff.
- Listening to and validating family members’ roles.

Table 1: A typology of family members’ beliefs about quality continence care

<table>
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<tr>
<th>Goal</th>
<th>Strategies/practices</th>
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| Keeping residents clean and comfortable | • Washing residents after incontinent episodes  
• Providing residents with continence products (i.e. absorbent disposable pads)  
• Selecting the rights pads for residents to use  
• Changing pads regularly  
• Ensuring the number of pads residents receive is commensurate with the frequency and severity of their incontinence |
| Interpreting residents’ behaviour | • Recognising and responding to residents’ verbal and non-verbal cues for toileting assistance  
• Interpreting residents’ behaviours with reference to pre-dementia lifelong values and beliefs |
| Prompting and assisting residents to the toilet | • Ensuring residents with dementia receive regular reminders and appropriate levels of supervision for all aspects of bladder/bowel management  
• Providing residents with timely and regular toileting assistance if they respond to this intervention |
| Employing knowledgeable and skilled staff | • Showing residents’ compassion and empathy when providing continence care  
• Ensuring staff are adequately trained about incontinence and can identify signs and symptoms that warrant further attention |
| Listening to and validating family members’ roles | • Listening to family members’ concerns  
• Enquiring about family members’ health and wellbeing  
• Acting upon family members’ concerns  
• Involving family members in their relative’s life and care |
Keeping residents clean and comfortable

Cleanliness and comfort emerged as salient and observable indicators of good continence care. For family members, cleanliness and comfort was evidenced by an absence of wet or soiled clothing. As one family member said:

"I'm pretty sure they've got some strategy because I haven't found her clothing hidden or anything like that in recent times (Int 45).

Family members expressed considerable distress at finding their relative in a wet or soiled state. Similarly, finding wet or soiled clothing hidden in a resident's room was indicative to them that the resident's continence care plan was not being enacted, or was ineffective. To some family members, it indicated that the resident had not received timely assistance to use the toilet, or that the incontinence aid (pad) provided to their relative was either inappropriate or had not been changed. The odour of urine or faeces also indicated poor quality continence care to family members. To most family members, a small volume of UI, such as a dribble contained in the pad was acceptable, but not visible UI, and no level of FI was acceptable.

Interpreting residents' behaviour

Family members were highly appreciative of nurses and care workers who were able to anticipate, interpret and respond to their cognitively impaired relative's need for help with continence care, and to interpret their behaviours. Some family members used terms such as "sneaky", or "weird" or "odd" to describe their relative's behaviour. As one family member said:

"At first she felt humiliated and dirty and all those things, and that set off odd behaviours like hiding dirty clothes and all of those things ... She was hiding them so that no one would find out. So that leads to all other kinds of sneaky behaviours (Int 45).

Family members interpreted and understood their relative's behaviour as a response to being embarrassed about being incontinent. According to family members, the diagnosis of dementia did not necessarily protect their relative from feelings of embarrassment. A daughter's comment exemplified this shared belief:

"She knows that she's been incontinent. She knows she's uncomfortable. That will cause agitation. She will even try and let people know by putting a clean pair of trousers on the end of her walker ... You know, just because you've got dementia, doesn't mean you lose your sense of smell and dignity (Int 01).

Another family member said "it's not that they're stupid and they don't know. Often they [residents] do know, but they just don't know how to do something". Having personal knowledge of the resident's pre-dementia lifelong values and beliefs was an important factor in being able to make sense of otherwise "sneaky", "weird" or "odd" behaviours. In one case, it helped a family member identify the cause of her mother's FI. She realised that her mother had an entrenched belief system that she needed to use her bowels every day. As
her mother was cognitively impaired, she was unable to recall having had a bowel action, and was receiving laxatives, which led to symptoms of FI.

Family members found residents’ unsuccessful efforts to conceal incontinence embarrassing and challenging. However, they also perceived a gradual lessening of residents’ embarrassment and odd behaviours over time, as dementia progressed. Alongside this change was an increased acceptance of wearing and using pads. When asked how a resident accepted wearing pads, a family member said:

_He seems to have accepted it [wearing pads] because the dementia’s come in now. So I don’t think he’s really 100 per cent aware of what he’s actually got on underneath. I don’t think he really realises that he’s got an actual pad on_ (Int 42).

**Prompting and assisting residents to the toilet**

Family members were very distressed when they perceived residents were not taken to the toilet frequently enough, particularly when residents responded positively to this intervention. In some situations, family members took an active role in helping to optimise a resident’s continence by taking them to the toilet when they were present at the facility, as indicated in the following comment.

_I’ll take her to the toilet every couple of hours. And she will use the toilet. I think that’s far more dignified than letting her walk around, you know, with a wet pad until it’s so wet that it has come through her trousers and she’s embarrassed. I know that I can toilet her every two hours and she can have a dry pad all day. But the carers don’t seem to pick up on that_ (Int 01).

Indeed, the same family member was so distressed about the infrequent nature of toileting assistance for her mother that she stated she was considering giving up work this year so that she can take care of her mum (Int 01).

In such situations, family members were unsure about what care their relative received, and were cynical, angry and frustrated about what they perceived was a gap between documented care and actual practice. One family member said she didn’t know where to direct her anger, particularly as she was aware the number of staff available to meet her mother’s needs was insufficient, and they were not individually responsible for the situation.

**Employing knowledgeable and skilled staff**

Staff knowledge and skill to understand and empathise with residents’ efforts to maintain continence, was a key indicator of quality continence care for families. As one family member said:

_I think it’s really important for people looking after those who are incontinent, to you know, have some empathy and treat those people with dignity_ (Int 01).

As previously indicated, family members recognised that their relative with dementia attempted to maintain continence up to a certain point in the dementia trajectory; however, their efforts to go to the toilet and use it independently were not always successful. If staff did not know how to interpret behaviours that indicated a person’s need for assistance to use the toilet, it resulted in the resident being incontinent. Hence, families were grateful when staff anticipated residents’ toileting needs and to pre-empt their need to void or defaecate.

Family members also appreciated it when staff responded creatively and flexibly to the unpredictable nature of their cognitively impaired relative’s behaviour. Indeed, all family members commented on the unpredictable nature of residents’ behaviours, that is, that their relative might know the location of the toilet one day and not the next. As one family member said:

_Well, what works one day, won’t work the next. Everyone with dementia is different_.

Thus, as one family member said:

... a one-size-fits-all approach to continence care would not work for residents with dementia.

For some family members, a salient indicator of good or bad care was staff knowledge and skill to identify signs and symptoms that warranted further investigation, and to have one’s concerns addressed. A family member described a situation in which her attempts to advocate for her cognitively impaired brother to receive medical attention were dismissed. It later emerged that he was in acute urinary retention for a number of days. She said:

_They [facility staff] kept poo-poohing the idea of something being wrong and told me he was putting it on. And, it turned out that the hospital put a catheter in and drained over two litres of urine from him. And, they said because his prostate was so enlarged he could not use — go to the toilet or_
use his bowels and what he was dribbling was just overflow. So he's had a catheter in ever since (Int 43).

When asked about quality continence care, some family members were highly complementary in their comments about staff. Box 1 reveals some comments that highlight their positive views. In these cases, family members were very appreciative of the care staff provided to their relative, and even accepted and understood occasional lapses in toileting that caused their relative to have an episode of potentially preventable incontinence.

**Box 1.**

- The carers look after my wife, and they do a fantastic job (Int 38).
- They are a good crowd at the facility (Int 38).
- They're 100% in my estimation — they're really, really good (Int 42).
- Very positive about the staff and the home (Int 42).
- They're brilliant in there. I can't fault the staff. So they're really good (Int 42).
- The way they're treating him there, I'm quite happy with it (Int 42).
- They're really good and, as I say, it's done on a regular basis so that they don't get sore or anything, you know (Int 42).
- You hear so many bad things about nursing homes, you know, and I was dreading him having to go into one but this one really is — you know, I'd give it 100 per cent because the girls are so good. They really are. They're really caring... (Int 42).
- Staff do not dictate the care — they offer and I reinforce (Int 45).

Two family members were less effusive about staff and the quality of care. One such participant, who was a former RN, expressed concern about the employment of personal care workers (PCAs) and their lack of educational preparation and limited English language skills. She attributed skin breakdown, a lack of toileting assistance, and failure to identify behavioural cues, to PCAs' lack of education.

**Listening to and validating family members’ role**

All family members indicated they valued being involved in their relative's life and care. Some felt more involved and welcomed than others. Family members who had negative experiences with staff had negative experiences of attempting to advocate for their relative. They wanted staff to listen to their concerns, and acknowledge their role as an advocate for the resident, as exemplified in the following transcript from a family member:

I think staff need to keep a very open communication channel with the relative who can be seen as the main carer, so that the person who — well, such as myself — can go and say, hey, look, I've just found all those dirty clothes in mum's wardrobe without an answer such as, Oh yeah, well, they do that. So I think listening to and addressing concerns from relatives certainly paves the way. It takes away that stress of, Oh, what am I going to do? The person involved who's the main carer — the relative or whatever — feeling that they're being listened to, feeling that they can discuss concerns very openly, and that they are then told this is what's going to happen as a result, or being asked what do you think should happen? (Int 45).

**DISCUSSION**

This paper reports qualitative findings from interviews with a small sample of family members about their understandings and expectations about 'quality continence care' for their relative living in a RAC facility. Based on their open-ended comments about continence care, shared indicators of quality continence care centre on practices that family members believe will maintain residents' cleanliness and comfort, interpret cognitively impaired residents' behaviours, optimise residents' continence and autonomy, identify and address underlying medical conditions, and validate family members' roles as advocates.

Prior research has drawn attention to problems and challenges for RAC facility staff and families in their attempts to meet residents' care needs in a holistic context. Indeed, Bauer's qualitative interviews with RAC facility staff suggested they found a number of family behaviours challenging and perceived the family as subordinate to their needs and wanted to retain control of the work environment. In our study, a lack of toileting assistance for cognitively impaired residents' caused considerable angst for family members. While family members' perceived toileting programmes could optimise their relative's continence, they struggled to understand why staff did not provide the requisite levels of assistance. Likewise, because family members had personal knowledge of their relative, and could interpret the relatives’ psychological and behavioural symptoms of dementia that indicated their need for assistance to use the toilet, they found it difficult to understand why staff were not equally knowledgeable and responsive.

In defence of care staff, not all residents who are cognitively impaired are able to behaviourally communicate their need for assistance. Indeed, the dementia trajectory is characterised by a progressive loss of global functioning, and in the latter stages includes a loss of ability to communicate verbally and/or behaviourally. Therefore, even with the best efforts, staff may be unable to reduce or prevent some residents from experiencing incontinence. However, when residents do behaviourally communicate their need for help, RAC facility staff should have the knowledge and skill to respond accordingly. Similarly, staff should consult with family members and invite them to help interpret their relative's behaviours so that residents' continence and dignity is optimised.
Based on the available data, we suggest that families with a relative in an RAC facility are engaged in a process of learning to accept their relative’s incontinence and the quality of continence care. The degree of acceptance is aligned with their overall expectations of, and satisfaction with, care and their relationship with staff. Acceptance does not come easily for some family members, particularly if they perceive their relative’s incontinence is caused by gaps in care. However, it would seem that having a good relationship with staff helps family members accept occasional lapses in care that result in incontinence.

Prior research on the experience of family members, when a relative is in an RAC facility, indicates they are dealing with difficult emotions associated with their relative’s transition, and many are in poor health themselves. Arguably, they should not have to additionally experience a struggle to have their opinions and concerns about the quality of their relative’s continence care heard. The findings point to the need for targeted strategies to improve communication processes between RAC facility staff and family members about incontinence and continence care, and for strategies to involve family members in an authentic caregiving partnership. Indeed, family members should be welcomed as key advocates and part of a team that has a resident’s physical and psychological wellbeing at the heart of their actions.

LIMITATIONS

The findings of the current study should be interpreted in light of the methods used to achieve the study objectives. They are based on an inductive content analysis of the perspectives of five next-of-kin family members. Despite using multiple means of communication, recruitment was particularly difficult, which may relate in part to the sensitive and difficult nature of the topic. Although the sample was very small, we were keen to give voice to family members to describe their experiences and opinions. Because of the small sample size, we do not claim data saturation or generalisability. It is possible the data may represent a group of people who wished to convey a particularly positive or negative set of attitudes. Indeed, the two former RNs’ comments indicated ‘insider’ knowledge that was not evident from participants who did not have a health professional background. Future research on this topic should explore how the influence of age, gender, cultural status, educational background, professional background, and publication bias can influence the results when interpreting and building on the findings.

Another consideration is the possibility that the opinion of family members about quality continence care may not be congruent with residents’ opinions. It was not our intent to compare opinions or seek to validate family members’ perspectives; however, it is noteworthy that prior research suggests that support persons such as family members may be able to make reasonably accurate inferences regarding the quality of life of individuals affected by UI.

CONCLUSION

The quality of continence care provided to residents living in RAC facilities and the methods used to measure it, have important personal, social, financial and policy implications. As the population ages, the prevalence of incontinence and dementia will increase, as will the demand for skilled care in the RAC sector. Alongside this demand will be an increase in consumers’ expectations about the quality of the care they receive, including continence care. The findings of this study emphasise the need for models of care in RAC facilities that offer a structured means to enhance partnership-centred care. The research resulted in a typology of family members’ beliefs and expectations about quality continence care. This typology could inform the development of future education programmes for the aged care workforce, as well as the development and implementation of a best practice guideline for quality continence care in RAC facilities. By providing important insights, the research contributes to international efforts to improve the quality of continence care for frail older adults.

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