



## Quality in residential care from the perspective of people living with dementia: The importance of personhood



R. Milte<sup>a,b,\*</sup>, W. Shulver<sup>a,b</sup>, M. Killington<sup>a</sup>, C. Bradley<sup>a,b</sup>, J. Ratcliffe<sup>c</sup>, M. Crotty<sup>a,b</sup>

<sup>a</sup> Rehabilitation, Aged and Extended Care, Flinders University, Adelaide, Australia

<sup>b</sup> NHMRC Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People, University of Sydney, Sydney, Australia

<sup>c</sup> Flinders Health Economics Group, Flinders University, Adelaide, Australia

### ARTICLE INFO

#### Article history:

Received 21 June 2015

Received in revised form 20 September 2015

Accepted 6 November 2015

Available online 23 November 2015

#### Keywords:

Nursing homes

Quality

Dementia

Qualitative

Quality of care

### ABSTRACT

**Background:** Providing quality care for people with dementia to meet the growing demand for services is a significant challenge to Australia and globally. When it comes to planning for current and future care needs, limited information is available on what people living with dementia and their family members consider the meaning of “quality” in residential care services.

**Objective:** To describe the meaning of quality residential care from the perspective of people with cognitive impairment and their family members.

**Design:** Qualitative data collection via in-depth interviews and focus groups was undertaken with people with dementia or cognitive impairment living in residential care or the community ( $n = 15$ ), and family members of people with dementia ( $n = 26$ ). Thematic analysis was undertaken to identify key themes.

**Results:** The theme of supporting personhood was identified as the overarching concept of importance to both people with dementia and their family members and as the foundation for quality care. There were subtle differences in how this concept was expressed by people with dementia themselves and their family members. However, for both groups, access to meaningful activities and opportunities to feel useful and valued were identified as important ways to support personhood in residential care. Separate to this theme of personhood, family members also talked about the importance of a supportive physical environment in the care home, while for the people with dementia themselves maintaining a connection with family was an important contributor to their experience of good quality residential care.

**Conclusions:** Supporting personhood was identified as a critical key concept underpinning quality residential aged care, from the perspective of both people with cognitive impairment and their family members. This highlights the important contribution that the psychological and social characteristics of care make to providing a good quality residential care experience from the perspective of consumers with dementia.

© 2015 The Authors. Published by Elsevier Ireland Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

### 1. Introduction

Dementia is an umbrella term, referring to a syndrome characterised by physical changes in the brain, which result in changes or impairment in cognitive, particularly in memory, thinking, behaviour, and ability to perform everyday tasks (World Health Organization, 2012). It is usually progressive in nature, and while seen more commonly in people as they age, it is not considered a normal part of aging. Providing care for people with dementia and other types of cognitive impairment to meet the growing demand for services is a significant challenge to Australia

and globally. There were 298,000 people living with dementia in Australia in 2011, with the number expected to triple by 2050 (Australian Institute of Health and Welfare, 2012). In 2012, dementia was recognised as the ninth National Health Priority Area for Australia, indicating a need to focus attention and effort on improving dementia care for the benefit of Australians now and in the future (Australian Institute of Health and Welfare, 2012).

Many people with dementia live in the community, but as the condition progresses and the cognitive and physical impacts become greater, they require increasing support to remain living at home. Eventually some people living with dementia may require more support than can be provided at home and move into a residential care facility for long-term care. Residents with dementia make up a significant proportion of the population in residential aged care facilities (RACFs); and over half of the

\* Corresponding author at: Rehabilitation, Aged and Extended Care, Flinders University, GPO Box 2100, Adelaide, SA 5001, Australia.

E-mail address: [Rachel.milte@flinders.edu.au](mailto:Rachel.milte@flinders.edu.au) (R. Milte).

permanent residents in 2009–2010 had a diagnosis of dementia (Australian Institute of Health and Welfare, 2012).

The provision of aged care services now and into the future has been an area of much debate, including how to design aged care services to ensure the quality of care (Department of Social Services, 2013 National Health and Hospitals Reform Commission, 2009). The term ‘quality of care’ or ‘good quality care’ is used aspirationally to describe a goal that health and aged care services should be seeking to provide. However, the concept of quality of care is broad, and many perspectives on the meaning exist. Largely, the focus in the published literature has been on measurement of clinical or process or organisational outcomes considered as indicators for good or poor quality care with the assumption that meeting these indicators will have benefits for ultimate recipients of the care (Castle & Ferguson, 2010; O’Reilly, Courtney, & Edwards, 2007). However, this focus on the clinical and organisational aspects of the provision of care may be missing broader aspects of the care or service provided in residential care that are of value to consumers.

Recently, there has been an increasing focus on the cost effectiveness of health and aged care services to ensure the best value for money spend of the tax-payer funded health dollar (Ratcliffe, Laver, Couzner, & Crotty, 2012). In order to maximise the value that the community gains from its health spending, services need to be provided in a way that provides the most benefit, value or improvement in wellbeing for the population. In addition, there is a concurrent movement towards meeting the needs and preferences of people with dementia and involving them in decisions about their lives and care (World Health Organization, 2012). Therefore, the incorporation of the ‘voice’ of consumers into the concept of quality residential care is needed. Previous studies have been undertaken to identify the determinants of good quality of life for residents in nursing homes, and have typically included psychosocial factors (such as relationships with family, peers and staff) and environmental characteristics of the home (such as any ‘institutional’ characteristics of the care home) (Bradshaw, Playford, & Riazi, 2012; Moyle, Fetherstonhaugh, Greben, Beattie, AusQoL Group, 2015). These studies have focused predominantly on residents living without cognitive impairment, and it is currently unknown whether people with cognitive impairment value similar aspects of the residential care experience.

Accordingly, the purpose of this study was to understand how people living with cognitive impairment, predominantly dementia, and their families perceive quality in residential care settings. We aimed to achieve an in-depth understanding of the concept of quality care directly from people experiencing these settings or who may also experience them in the future. To undertake this research, we identified the following: (1) What is the meaning of ‘quality of care’ in a residential care setting for people living with dementia and their family members? (2) What are the key factors that ensure ‘good quality’ care from the perspective of consumers of residential aged care? (3) What are the key factors associated with ‘poor quality’ care from the perspectives of consumers?

## 2. Methods

### 2.1. Recruitment

Participants were recruited from the three RACFs in South Australia and NSW, as well as via support networks for people with cognitive impairment and their family members. Participants had to have a level of cognitive function which allowed them have a conversation with the researcher. Participants were recruited purposefully with the aim of providing perspectives from a number of key consumer groups with an interest in the residential aged care setting. This included recruiting both men and women,

older people with cognitive impairment or dementia living in residential care, people with family members living in residential aged care, and people living with dementia in the community. This study was approved by the Flinders University Social and Behavioural Research Ethics Committee (Approval number: 6446).

### 2.2. Interviews with people with cognitive impairment

A series of face-to-face interviews were conducted by members of the research team who were experienced in interviewing people living with cognitive impairment. The interviews were semi-structured and responded to the cognitive ability of the individual being interviewed to ensure they were able to participate fully. The duration of the interviews was approximately thirty minutes on average. The interviewer also completed a questionnaire with the individual to ascertain some basic demographic information with assistance from family members if needed. The level of cognitive impairment of the participants was also collected using the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). This questionnaire has 10 questions covering a wide range of cognitive functions including short and long-term memory, orientation to surroundings and current events, and ability to perform serial subtractions. The SPMSQ has been found to correlate significantly with scores generated by the widely used mini-mental state examination (Roccaforte, Burke, Bayer, & Wengel, 1994; Smith, Tremont, & Ott, 2008). The SPMSQ was chosen for its brevity, and ability to be undertaken via telephone if required, and for its high level of correlation with the more widely used mini-mental state examination.

### 2.3. Focus groups

Family members (or in a few cases close friends or guardians) of people with cognitive impairment participated in the research via focus groups, facilitated by two trained members of the research team. The focus groups were semi-structured with the discussion focusing initially on what were important features of ‘good quality care’ in a residential care setting. The facilitators aimed to involve all members of the focus group in the discussion and to encourage discussion and elaboration of key ideas brought up by members of the group by the rest of the group. The participants also provided some basic demographic information. The focus groups lasted for approximately one hour. Discussion was digitally recorded to allow for transcription.

### 2.4. Analysis

Recordings of the focus groups were transcribed verbatim by a professional transcription service SmartDocs Pty., Ltd<sup>®</sup>. Thematic coding procedures were then undertaken utilizing NVivo version 10. The analysis was based on the recommendations for conducting qualitative data analysis with a view to producing attributes for incorporation into the development of a new preference based instrument to measure the quality of care in RACF (Coast et al., 2012). Following these recommendations, the analysis was inductive with all themes generated from the data itself without attempting to link these back to existing theories in this coding stage. The focus of the research was to develop new ideas about what the provision of good quality care means rather than determining the validity of previously generated theories, particularly given the limited literature currently available on the meaning of these concepts to people with cognitive impairment or dementia. The constant comparative analysis technique was used in the coding, which involved analysing the transcripts in batches, with this coding informing future data collection and coding. An initial process of ‘topic coding’ was undertaken, which served to

organise the data by creating derivative categories from each transcript. These were treated as a provisional framework for ‘analytic coding’ and ‘coding on’, involving interpretive review of the material and the ongoing development of overarching themes and conceptual categories (Richards, 2005). To increase the validity of the findings, categories and themes were discussed and verified with the other researchers on the team following both the initial and coding on phases. The data collected from family members of people with cognitive impairment were analysed separately to the data collected from the people themselves and will be presented as such. For each theme, key quotes illustrating the meaning of the themes were determined and are presented to provide context.

### 3. Results

The data collection was conducted between June and September 2014. A total of 41 people participated in the data collection; 26 family members of people living with cognitive impairment, and 15 people living with cognitive impairment (12 currently living in RACFs and three living in the community). Table 1 gives some basic demographic information for the participants. The mean number of errors on the SPMSQ for participants with cognitive impairment was 7 (SD 2) indicating moderate cognitive impairment. However the number of errors recorded for participants ranged from 3 (indicating mild cognitive impairment) up to 10 (indicating severe cognitive impairment).

The key themes generated from the analysis of the qualitative data collection from people with cognitive impairment and from family members are outlined in Tables 2 and 3. Further explanation of these themes can be found in the following sections. The quotes from the people living with cognitive impairment are identified by their gender, their status as community dwelling or living in residential care, and a unique identifier based on the chronological number of the interview. For family members, the quotes are labelled with the number of the focus group.

#### 3.1. People living with cognitive impairment

There were two key themes underpinning the concept of good quality care identified from the analysis of the qualitative interviews with people living with cognitive impairment; these were 1. Good quality care supports personhood and 2. Good quality care maintains connection to family. How good quality care could maintain a sense of personhood was expressed through four sub-themes: (i) choice, freedom and self-determination, (ii) meaningful activities, (iii) feeling useful and valued, and (iv) respect for possessions and personal space (Table 2).

#### 1. Good quality care supports personhood

**Table 1**

Demographic characteristics of all participants ( $n=41$ ).

Characteristic	People with cognitive impairment ( $n=15$ )	Family members ( $n=26$ )
Gender $n$ (%)		
Females	9 (60)	18 (69)
Males	6 (40)	8 (31)
Mean age (SD)	79 (11)	75 (9)
Highest level of education $n$ (%)		
No qualification	3 (20)	1 (4)
Completed high school	6 (40)	10 (38)
Undergraduate or professional qualification	4 (27)	8 (31)
Post graduate qualification	2 (13)	7 (27)
Born in Australia $n$ (%)	12 (80)	20 (77)
Language spoken at home is English $n$ (%)	14 (93)	25 (96)

Abbreviation: SD = standard deviation.

Throughout the interviews, participants consistently equated providing good quality care with being identified and respected as a person with individual likes, dislikes, preferences and needs. Being able to express personal preferences, and having them respected permeated virtually all discussion surrounding the meaning of good quality residential care. Being labelled as a diagnosis or a behaviour and no longer seen as a whole person with a life was seen as dehumanising and disrespectful and contributing to poor outcomes in residential care.

*“I have a . . . brain. I have a brain and- and I use it . . . and if it doesn't suit people out there, well that's bad luck <laughter>”*  
[Male, Resident, 15]

One participant in particular expressed that without a respect for personhood underpinning the other physical aspects of care that are provided, the concept of good quality care would be lost. He described this situation as:

*“They don't talk to you. They sort of—how do I . . . They treat me like they're in hospital, that they're doing something for you. You know what I mean? There's a difference.”* [Male, Resident, 6]

Participants also spoke about the importance of being treated respectfully by staff:

*“[Hospital name] didn't respect me. I didn't feel they had any respect for me- . . . I've got respect for them here [at the facility], and everything else you can see here. I can get access to everything.”* [M, Resident, 6]

#### i Choice, freedom and self-determination

Whilst some participants were happy to fit into facility routines, most spoke about the value of having as much independence, autonomy and flexibility in their daily routine and freedom of movement as possible. Being able to go outside when they wished, and not be “locked” inside was particularly valued. In addition, participants felt that the delivery of care must cater to individual preferences, needs and personalities. In fact, some participants expressed frustration when they were not able to continue living their lives the way they wanted to due to perceived pressure to fit in with the ‘status quo’ or routines of the facility that they had moved into.

*“It depends on the person of course, some people are very private in their way, where they live and what they do, and others are quite laid back, to use a term, they don't seem to get anxious about anything. And, how the person or people are is- needs to be assessed so that nobody is put in an awkward position with something coming differently from what was expected.”* [M, Resident, 2]

**Table 2**  
Key concepts of good residential care as described by people with cognitive impairment.

Key themes	Subthemes	Quotes
(1) Good quality care supports personhood	(i) Choice, freedom and self-determination	"No one likes to be sitting around with no say in what they doing <laughter>." [M, Resident, 6]
	(ii) Meaningful activities	"I've still got blimmin' hands and, you know, it's only this little blimmin' worm in here" (points to head)—[M, Community, 4]
	(iii) Feeling useful and valued	"Well if you do little tiny things for them . . . For the staff" [F, Resident, 8]
	(iv) Respect for possessions and personal space	"I don't have a key that I can lock my door. I have to sit and watch where I am. I sit just down the road there, just outside there, so I can watch me door when people come in out and that . . . I haven't got a key for my door, which I would like to have." [F, Resident, 5]
(2) Good quality care maintains connection with family		"And a place that welcomes family in." [F, Resident, 15]

Further, participants indicated that being able to have control over their daily routines provided a sense of normality and freedom in their life. When participants were able to have sense of control over their daily lives, they identified this as positive and as a highly valued characteristic of the facility.

#### ii Meaningful activities

Having access to activities or interests during the day was seen as very important to a good quality residential care experience. This was seen as something that needed to be provided within the facility. It was seen as vital to avoid boredom and as an integral part of the care that should be provided, highlighting that to consumers good 'care' does not mean just taking care of the person physically, but also considering social and emotional needs. Provision of meaningful activities was an important aspect of supporting personhood. It was important to participants not only that they are able to participate in activities, but that they are able to continue to be who they are by participating in activities that are *meaningful* to them. For the activities to be meaningful to the participant, there was a sense that activities should be tailored to the individual's interests and preferences, rather than people being offered more traditional diversion activities that may provide no context to participants. Being able to continue to enjoy activities that they had participated in previously was a further key aspect that made activities meaningful. For example, one man described it was important to him to exercise at a gym a few times during the week. This was something he had done previously in his life, but had slipped away and he had not kept up with. However, after he received a diagnosis of dementia, he decided to take up exercising again. He described exercising at the gym as giving him back his 'dignity' by providing a sense of continuity with his life prior to his diagnosis. Providing this dignity and sense of continuity made this particular activity highly 'meaningful' to him. In contrast, this participant expressed that he tried another similar activity that he thought he would enjoy—sailing, however, he found that he did not enjoy it at all. This was an activity that he had not done previously, and thus didn't have a previous connection with. Therefore, he did not continue with that activity, but was happy to continue going to the gym for exercise.

*Participant: "[Exercising at the gym] gives you your dignity back for a start, number one . . . because I walked in there and I felt straight away, as soon as I walked in there and signed up, something happened to me and my body and that's saying "you've been here before" and I hadn't been in the gym for 14 years and all of a sudden something clicked . . ."* [M, Community, 4]

Other participants with cognitive impairment not currently residing in a RACF described an expectation that people with dementia will give up their previous life, including the very things that gave their life meaning before a diagnosis, and that ultimately

this would have a negative impact on their quality of life and on the progression of the disease.

*"the day I was diagnosed I was told to give it all up. Give up work, give up study, that'll be bad for you, go home and live the time you've got left; whatever that means after you've given up everything you like . . ."* [F, Community, 6]

While participants were keen to keep doing as much activity as they could, they also expressed an understanding that as their disease progressed they would be unable to do everything they once were able to. There was a sense of grief and sadness associated with this realisation, and frustration as they identified particular symptoms of disease that impacted on their abilities. There was a sense with some participants that if it wasn't for this particular barrier (a particular symptom) they would be able to continue with this particular activity and derive enjoyment from it;

*Interviewer: "Are there- activities that are tailored for you at all that you can do?"*

*Participant: "Not really no. I-I've got a bit of a problem with tailoring things to me, because whatever I do I have to do with the hands right, and I have to use my hands on things like sanding down the frame of the- of the thing."*

*Participant's wife: "But that was too hard. You couldn't do it."*

*Participant: "I know it was . . . It was the breathing that beat me, because it was puffing up bits of . . . That's why I couldn't breathe."* [M, Resident, 15]

#### iii Feeling useful and valued

Being able to make a contribution to the facility by helping with jobs and assisting other residents gave some participants living in RACFs a sense of being useful and valued. Feeling useful could also be through contributing to family life, through attending or being included in important family milestones, or providing advice to family members. They derived a great sense of personal satisfaction from this. Alternatively, for some participants, being able to contribute to small domestic tasks gave them a sense of normality or a continuation of their everyday lives prior to admission to a RACF. Having the opportunity and being supported to contribute to these activities was identified as an important part of a positive residential care experience.

One participant living in the community described how important it was for him to be engaged in activities that were worthwhile and that used his skills and brain, and that having the opportunity to contribute in this way within the residential care setting would support the dignity of the individual.

*"I can't, yeah, I can't do that because you're not actually using—to me you're not actually using your brain. Like I've already told you that—what was it, something that, you know, oh our dignity. Get that back and you'll see we all blossom."* [M, Community, 4]

#### iv Respect for possessions and personal space

Finally, it was important to participants that the aged care home showed respect for the possessions and personal space of the individual. The importance of having their own personal space, and control over that space as much as possible was expressed by the participants. For the participants, the sense of having a space of their own symbolised a sense of respect for them as a person and this was highly valued.

*Interviewer: "And the other thing I notice is that you have the key around your neck for your room. And that's your room and no one goes in it unless you give them permission."*

*Participant: "Yes VERY important . . . I just think it's no body's business what I do and I enjoy myself without I just think I enjoy it when I am in my room, it's something mine" [M, Resident, 9]*

Moreover, for participants who perceived they did not have control over their personal space and possessions, this caused some anxiety and weighed on their minds. One participant described how she decided on where she would sit during the day based on being able to watch over her room, which she was not able to lock.

#### 2. Good quality care maintains connection with family

In addition to the identified key theme of personhood and its sub-themes, several participants highlighted how important their connection with their family was to their lives, providing an anchor point to their daily life.

*"Family that's the most important thing without any shadow of a doubt." [M, Resident, 15]*

Several participants described having access to their spouse or family as a key driving factor in whether they would be happy living in a residential care facility or not. They described often that proximity to family was an important driving factor in their decision on the location of their preferred residential care facility. In addition, it was extremely important that family could not only access the facility but felt welcome when they visited the facility. Losing contact with family was a key source of anxiety for the participants, especially during their transition into residential care for the first time. This was especially so for participants who were still married when they entered residential care, and they expressed strongly their status as continuing to be married in the interviews and wanted this recognised.

*"What was important to me was access to [wife], and access to some sort of freedom regardless of how- how the freedom was provided but, you know, the one thing that really just put me off was people saying, oh yeah, "You can't see your wife", you know, and I thought, well that, you know, that's not on. I'm not going to be in that." [M, Resident, 6]*

*"I'm not a single bloke sitting in the corner. I'm a married person, and I married to a person who I love very, very much and I really just like to think that perhaps she might like me that much and in your case I do, and I have no problem with- with the setup, you know. It's just straight out that's the way it is." (M, Resident, 15)*

Visits from family were very much looked forward to, and participants wanted the facility to support family to visits as often as they were able to. A sense of being separated from their family members triggered feelings of grief and loss of an important connection. Maintaining this connection was seen as important to support the wellbeing of the individual, through providing social support, a counterpoint to their existence, and a connection with their lives prior to diagnosis with dementia and living in residential care.

One participant expressed his grief at being separated from his wife when his increasing need for support resulted in him moving into residential care. This participant's wife was able to live close by to the facility and to visit everyday. For him, having a residential care home that enabled his family to visit often was the most important component to support his wellbeing and quality of life—he described his wife and her visits being an 'anchor' in his life. This participant described his preferred residential care home as 'a place that welcomes family in' showing that for people with dementia, a residential care home is expected to do more than just tolerate family but to support the person with dementia to maintain a connection with family, to be providing care that meets their needs and concept of quality care.

#### 3.2. Family members or friends of people with cognitive impairment

Supporting personhood was identified again as a highly important concept in quality of care in the themes drawn from the analysis of the data collected from family member (or friends). This had a similar meaning to the concept of supporting personhood expressed by the people with cognitive impairment themselves, but it was expressed through slightly different subthemes of (i) individualized care, (ii) Access to meaningful activities, (iii) Opportunities to feel useful, and (iv) Supportive healthcare and medical management. Separate to this theme of personhood, family members also talked about the importance of a supportive physical environment in the RACF. The concept of a supportive physical environment was underpinned by the sub-themes of (i) a 'homelike' environment, and (ii) resident safety (Table 3).

##### 1. Good quality care supports personhood

It was of utmost importance to family members and close friends, that people living with dementia should be respected as people and not stigmatized due to their diagnosis. Participants described their perception that society treated those with declining health due to cognitive impairment and dementia are viewed differently to those with declining physical health.

*"And we all come to this . . . the thing is, if your body is going downhill physically, nobody bats an eyelid, so why should it be any different if it's the brain that's doing something different?" [Focus Group 1]*

There was a strong desire to eliminate what was seen as a stigma in general society towards people with dementia and cognitive impairment, and removing this was seen as a key foundation for providing good quality care. One participant described that they thought that the best way to eliminate this stigma was by example, by people living the experience of caring for someone with dementia showing that they were proud to be caring for someone with dementia.

##### i. Individualized care

Family members felt that 'good quality' care was tailored to the needs and preferences of the individual. Providing care that was tailored to the individual was seen as crucial to achieving good outcomes for the person. This was seen as particularly important in the care of people with dementia where their ability to communicate their needs may be impacted by the symptoms they were experiencing. Therefore, kind, respectful staff were considered highly important, who were able to get to know residents, enabling them to tailor care and management to individuals. For example, providing enough support to assist a person with the activities of daily living, but not too much support

so that they lost the ability to do these tasks themselves prematurely. Some felt that this was achieved satisfactorily at their family member's facility, and others did not.

Family members perceived that shortcomings in the level of care often stemmed from systemic problems, particularly understaffing, resulting in workers who did not have enough time to spend with and get to know individual residents, whether they desired to or not. They perceived carers as pushed, tired, exhausted, without adequate time to spend with residents to provide individualised care. Without adequate time and energy, care was delivered in a 'one size fits all' and generic manner instead of trialling individualised approaches to caring for each person.

*"The people, the carers don't have a lot of time. They're being pushed . . . I think they're just tired, exhausted. They haven't got that time to spend, that quality time with the residents. They haven't got the quality time."* [Focus Group 1]

Poor training, in addition to lack of time, and particularly a lack of specific dementia training was barrier to providing individualised care in the residential care setting. Family members described that they felt the training to become a carer was relatively fast, and that it didn't equip staff coming out of the training with enough knowledge of dementia and its impact upon the care needs of people in residential care. In addition, the lack of training was seen as feeding into a perception of being a carer as a 'last resort' as a career.

## ii Access to meaningful activities

Family members felt that many residents suffered from a lack of stimulation, and described that they felt that television was often the only stimulation offered day to day.

*"He is bored out of his brain. Absolutely bored."* [Focus Group 3]

For an activity to be effective at alleviating this boredom it need to be something the individual enjoyed, that was difficult enough to require concentration and engagement but not too difficult for them to complete. They described that in good quality care, residents would have access not just to standardised activities, but have the opportunity to engage in activities that were meaningful and individualized to their own history, preferences and needs. Another key consideration that defined a 'meaningful activity' was whether it was familiar to the individual or relevant to their background. For example, family members described activities linked back to childhood memories for residents, describing them as a 'trigger for happiness'. Another family member described that her mother continued daily walking when admitted to residential care because *"what's ingrained seems to last longer"* [Focus Group 3]. Other participants suggested that if their family member had been a solitary person and enjoyed solitary activities prior to their admission, then they should be supported to undertake these activities, rather than being expected to participate in the usual group activities offered. Participants also suggested that the current activities being offered were often focused around things that women traditionally enjoyed doing, and that often this resulted in the men feeling left out or not engaging with the activities offered. A key focus of this was that the activities needed to be individualised for each person, rather than an approach of offering a generic program of activities as the only option. For example, one participant described that her husband did not enjoy the usual activities offered in the program at his current facility, but that he did enjoy undertaking practical tasks such as looking after the garden, as this was something he had done when living at home. Therefore, she had asked for him to be supported to undertake this as an activity with the facility. It was important that activities were designed to maximise engagement from the residents, as family

members believed that without activity and engagement in the nursing home over a long period of time, it contributed to resident's cognitive and physical decline.

## iii Opportunities to feel useful and valued

Further to this, family members described a desire in residents living in care to still be 'useful' and contribute to life within the care home by doing practical tasks. This was seen as a continuation of their life prior to admission to residential care, respecting the history of the individual, as well as providing 'something to do'. 'Good quality' care encourages opportunities for residents to feel useful.

One family member described how his wife would try to undertake tasks within the nursing home that showed that she remembered her role as a younger woman as a nurse, and that she wanted to continue this role as something familiar to her within the RACF. Her being able to continue this role within the facility in some form was viewed positively and as respecting her individual needs. There was a sense that allowing residents to continue their expression of previous roles supported their wellbeing and therefore was considered a part of quality care. Conversely, if there were no opportunities for an individual to continue to contribute to society and feel useful, or if they were blocked from taking these opportunities, this would be considered detrimental to the individual and not in the spirit of good quality care.

## iv Supportive healthcare and medical management

Again reflecting the key theme of personhood, family members thought that healthcare should be individualized to the resident. Good quality healthcare would be holistic, and not confined to dementia management alone. Access to 'extra' healthcare services, such as podiatry, dental and allied health were valued. It was felt that with access to good quality healthcare services, which considered a broad range of components of health, would improve the outcomes of the individual.

*"I think it goes to investigation; to find out whether that person is (a) depressed; (b) in lots of pain or whether it's the dementia . . . because a lot of people with dementia actually have pain and, you know, they're calling out a lot and you'll find that once you alleviate the pain, if they've had arthritis before, they've still got it, and you take that away, then they're not quite as hard to look after."* [Focus Group 1]

Some family members considered physical activities and exercise programs important to maintain mobility and quality of life. Family members identified that they thought it was important to consider and maintain physical health for people with cognitive impairment, rather than just focusing on basic activities of daily living support.

## 2. Supportive physical environment

It was felt that the physical layout of RACFs should be able to cater to individual preferences (e.g. for privacy, social interaction and activities). Although some family members did not think that all residents would be particularly aware of their physical surroundings, others spoke about the importance of a 'homelike' environment, safety aspects and cleanliness.

### i. It's a 'home'

Family members felt that the physical layout of RACFs should be as 'homelike' as possible. That residents be respected in 'their home' was also important.

*"When mum came here, one of the first things they said to her was, "This is your home now. When the staff step through your doorway, they are to treat you with the same respect that they would if they'd come into your home" . . . But I thought that was really important." [Focus Group 1]*

A homelike feel was contrasted with a clinical, institution-like feel, which was not preferred. Family members indicated that the building should blend in with the community, it should be easy to access from the community, as well as for residents to reach out into the community. One participant described how having a more homelike physical environment made it an easier for her to transition her husband into aged care, rather than placing him in a more clinical environment, which she felt would make him anxious.

*"I think the buildings should blend in with the community. It's part of the community. And so I would be focusing on environments that look like houses rather than building them up stories high basically and making them look like a hotel. I think the generation that I come from really appreciates values like homes that you've lived in for a long time." [Focus Group 1].*

Having access to private spaces outside of their own room, for example small lounges, or reading nooks, or having ornaments on the tables was thought to create a homelike feel to a care home. Family members also expressed a preference for cleanliness of RACF to create a more pleasant environment for those living and working there. For another participant, they described how access to space with trees and gardens could make a facility more 'homelike' and preferred, because it allowed their family member to reconnect with memories of their childhood.

*"For my mother-in-law, it was to take her back to the trees and the hills and the physical outside surroundings that reminded her of her childhood. That that was her number one top of the list. I mean we were looking for proper safe care as well, but with that particular facility, that was right up there because that's where she was going to feel at home." [Focus Group 2]*

## ii Safety

Family members were also concerned that the physical layout of RACFs incorporated safety features. However, family members

understood there was a balance between managing risk and having a safe environment, and other aspects of good quality care, such as maintaining physical health through physical activity, and respect for the individual's control over their own decisions.

## 4. Discussion

There have been few previous studies of the perspectives of individuals with cognitive impairment and their family members on residential care quality, despite individuals with cognitive impairment forming a large proportion of the population accessing these services. Coughlan and Ward (2007) undertook interviews with residents upon moving from an old hospital style RACF to a new purpose build facility, but only included people from a single facility and those with no or moderate cognitive impairment rather than the more severely cognitively impaired people we were able to include in our study. Tester, Hubbard, Downs, MacDonald, and Murphy (2004) and more recently in Australia Moyle et al. (2015) conducted interviews with people living in residential care with more severe cognitive impairment. However, these studies focused on outcomes, considering concepts of quality of life. In contrast our study focused on the process of care delivery and perspectives of quality of care rather than quality of life, and included both people with dementia and family members of people in residential care as we considered both groups to have an interest in good outcomes in residential care from a consumer perspective.

For both people with dementia and the family members in our study, a highly important concept identified was that good quality care is that which supports personhood. The concept of personhood has been described previously in relation to dementia care, particularly by Kitwood and Bredin (1992). Kitwood and Bredin (1992) describe how being a person implies that someone has a certain respect and status in society—they are afforded certain rights and responsibilities. They identified maintaining the person with dementia's personhood as critical to providing dementia care, which they argued was a concept that had been lacking from traditional 'medical' views of dementia care as evaluation and management of an increasing accumulation of 'problems' associated with the assumed declining cognitive ability of the individual. They described a list of twelve indicators of well-being in dementia care, which are: (1) Assertion of desire or will, (2) the ability to experience and express a range of emotions, (3) initiation of social

**Table 3**

Key concepts of good residential care as described by family members of people living in residential care.

Key themes	Subthemes	Quotes
(1) Good quality care supports personhood	(i) Individualized care	<i>"And I think they also realise that if she sits and doesn't get her food fairly promptly, she's likely to get up and wander around &lt;laughs&gt; and talk to other people and they want them seated. So, quite often when I've taken her to the dining room there are a couple of little club sandwiches there for her to start her meal, before the soup. Yeah they're responding well to individual needs." [Focus group 2]</i>
	(ii) Access to meaningful activities	<i>"And every resident when he comes, they should know what he needs . . . They don't have that. They all just put them in their corner there, put the video there and just leave them there." [Focus Group 1]</i>
	(iii) Opportunities to feel useful and valued	<i>"And she's still wanting to continue with her nursing role in the nursing home and sometimes that's viewed as interference. And again it's I think it's a matter of adequate recognition by the staff of what the individual's background has been and how they might want to continue to feel useful and helpful in society." [Focus Group 1]</i>
	(iv) Supportive healthcare and medical management	<i>"My father was very physically active before coming in here, right til he was put into hospital for four weeks. And so he used to walk everywhere. And now I've watched his gait get shorter, and shorter, because he's lying in his bed, and just walking to the dining room . . . because keeping your body active is such an important part of the health, that I presumed that that would be looked after. [Focus group 4]</i>
(2) Supportive physical environment	(i) It's a 'home'	<i>"And I thought, well this isn't going; because he didn't want to leave home, and I can't take him from his usual home with a beautiful garden and put him into a hospital room, and expect him to be relaxed . . . So I mean this place I just found very homely" [Focus Group 4]</i>
	(ii) Safety	<i>"Understand this because they have falls sort of every day occurrence, but to me—to prevent people from falling they restrict them, instead of allowing them to be physically active and encouraging people to be physically active so they get stronger and have better co-ordination and balance and all those things. See, the more you restrict them or limit them, the more likely they are to have a fall." [Focus Group 1]</i>

contact, (4) affectional warmth, (5) social sensitivity, (6) self respect, (7) acceptance of other dementia sufferers, (8) humour, (9) creativity and self-expression, (10) showing evident pleasure, (11) helpfulness, and (12) relaxation.

There are a number of parallels with the subthemes expressed in our study as part of the major theme of 'good quality care supports personhood' and those expressed by Kitwood and Bredin (1992). Supporting this overall theme for individuals with cognitive impairment living in RACFs was the extent to which they had choice, freedom and self-determination, access to meaningful activities, opportunities to feel a useful and valued member of society, and respect for possessions and personal space. In addition, helping maintain a connection with family was viewed as part of a good quality residential care experience, for example a location close to family, and a place where family felt welcome to visit frequently were both seen as highly important. Family members indicated that the overarching concept of personhood was achieved through providing individualized care, access to meaningful activities and opportunities to feel useful and valued, and supportive healthcare and medical management.

There are some parallels in the findings from our study and the recent study conducted by Moyle et al. (2015) to investigate the influencers on quality of life as reported by people living with dementia in long-term care. For example, both studies reported the central importance of maintaining independence. This overlap between the themes identified through previous work on determinants of quality of life and our discussion of quality of care highlights an important point in the conceptualisation of quality of care—that from the perspectives of people with dementia and their family members supporting quality of life and wellbeing are important components of quality of care.

However there were some key components identified by the participants in our study in relation to the quality of care that were not identified by Moyle and colleagues as influencers for quality of life, indicating that the concepts of quality of life and quality of care are not entirely inter-changeable. For example, in discussing the determinants of quality of care, our participants also discussed aspects of the medical and physical care provided, and identified supportive healthcare and medical management as a key component of quality of care. In addition, they identified characteristics related to the physical environment of the home as important to provide good quality care, such as having a 'home' like, safe, and clean environment, and there being a sense of respect for their possessions and personal space. We also included family members in our study, which could account for some of the differences in themes identified. However, overall, it appears that to people with dementia, and their family members, maintaining quality of life and wellbeing of the person in care is a highly important outcome of good quality care, in addition to aspects of the physical care and support provided within the setting. This observation concurs with the previous work conducted by Coughlan and Ward (2007) and Tester et al. (2004), highlighting the importance of the psychosocial characteristics of care provided in addition to the physical support and healthcare provided in the eyes of residential aged care consumers.

#### 4.1. Future directions

This is the first known study to specifically target the views of people living with cognitive impairment and dementia and family members as to the key components of quality care from their perspective in the residential setting. A major contribution of this study is to highlight the ability of those with cognitive impairment (including severe cognitive impairment) to participate in research, an important concept given the usual exclusion of those with cognitive impairment from research (Taylor, DeMers, Vig, &

Borson, 2012). However, with the growing numbers of older adults worldwide with cognitive impairment, exclusion of this group from research, especially in fields of geriatrics or health and aging services is no longer viable (Taylor et al., 2012). By using in-depth interviewing adjusted for the cognitive ability of the participants, we were able to gain the perspectives of people with a wide range of cognitive abilities, including those only mildly impaired, through to very severely impaired residents. This demonstrates the ability of those with cognitive impairment to participate successfully in research if strategies are put in place by researchers to support their participation. The gain for researchers for putting these strategies into place, is being able to access the key perspective of people with cognitive impairment on issues of relevance to them, enriching our understanding of this condition, and leading to better care and services for this population group for the future.

Quality of care has often been defined in the literature by the presence or absence of certain indicators (for example, focusing on the clinical aspects of the care such as number of pressure ulcers, falls, restraints, loss of weight, Castle & Ferguson, 2010). The resident's voice has been missing from much of the consideration of quality of care in residential care until recently (Castle & Ferguson, 2010). However, this perspective limits the concept of 'care' provided within the residential aged care facility to health and medical components, and does not consider the psychological and social aspects of care which are integral to concepts of wellbeing (Grad, 2002). In our study of people with cognitive impairment and their family members, we found that the psychological and social aspects of care, particularly the interactions between the staff, the environment, and the resident, were considered just as important a contribution to the concept of good quality care as the health-related and physical aspects of the care setting. Therefore, future interventions to improve quality in residential care should include consideration of the social and psychological aspects of the care provided in addition to the health-related and physical aspects of the care environment to fully support the wellbeing of residents.

#### Acknowledgements

These authors gratefully acknowledge funding provided by the National Health and Medical Research Council (NHMRC) Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People. The contents of the published materials are solely the responsibility of the Administering Institution, Flinders University, and the individual authors identified, and do not reflect the views of the NHMRC or the RACFs involved in the research.

#### References

- Australian Institute of Health and Welfare (2012). *Dementia in Australia*. Canberra: AIHW.
- Bradshaw, S. A., Playford, E. D., & Riazi, A. (2012). Living well in care homes: a systematic review of qualitative studies. *Age Ageing*, 41, 429–440.
- Castle, N. G., & Ferguson, J. C. (2010). What is nursing home quality and how is it measured? *Gerontologist*, 50, 426–442.
- Coast, J., Al-Janabi, H., Sutton, E. J., Horrocks, S. A., Vosper, A. J., Swancutt, D. R., et al. (2012). Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. *Health Economics*, 21, 730–741.
- Coughlan, R., & Ward, L. (2007). Experiences of recently relocated residents of a long-term care facility in Ontario: assessing quality qualitatively. *International Journal of Nursing Studies*, 44, 47–57.
- Department of Social Services (2013). *2012–2013 Report of the operation of the aged care act, 1997*. Canberra, Australia: Australian Government.
- Grad, F. P. (2002). The preamble of the constitution of the World Health Organization. *Bulletin World Health Organisation*, 80, 981–984.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing Society*, 12, 269–287.

- Moyle, W., Fetherstonhaugh, D., Greben, M., Beattie, E., & AusQoL Group (2015). Influencers on quality of life as reported by people living with dementia in long-term care: a descriptive exploratory approach. *BMC Geriatrics*, 15, 50.
- National Health and Hospitals Reform Commission (2009). *A healthier future for all Australians—final report of the National Health and Hospitals Reform Commission*. Canberra, Australia: Australian Government.
- O'Reilly, M., Courtney, M., & Edwards, H. (2007). How is quality being monitored in Australian residential aged care facilities? A narrative review. *International Journal of Quality in Health Care*, 19, 177–182.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of American Geriatric Society*, 23, 433–441.
- Ratcliffe, J., Laver, K., Couzner, L., & Crotty, M. (2012). Health economics and geriatrics: challenges and opportunities. In C. S. Atwood (Ed.), *Geriatrics* (pp. 209–234). Croatia: InTech, Rijeka.
- Richards, L. (2005). *Handling qualitative data: a practical guide*. London: Sage.
- Roccaforte, W. H., Burke, W. J., Bayer, B. L., & Wengel, S. P. (1994). Reliability and validity of the short portable mental status questionnaire administered by telephone. *Journal of Geriatrics Psychiatry Neurology*, 7, 33–38.
- Smith, M. M., Tremont, G., & Ott, B. R. (2008). A review of telephone-administered screening tests for dementia diagnosis. *American Journal of Alzheimer's Disease Other Dementias*, 24, 58–69.
- Taylor, J. S., DeMers, S. M., Vig, E. K., & Borson, S. (2012). The disappearing subject: exclusion of people with cognitive impairment and dementia from geriatrics research. *Journal of American Geriatrics Society*, 60, 413–419.
- Tester, S., Hubbard, G., Downs, M., MacDonald, C., & Murphy, J. (2004). What does quality of life mean for frail residents? *Nursing & Residential Care*, 6, 89–92.
- World Health Organization (2012). *Dementia: a public health priority*. Geneva, Switzerland: Department of Mental Health and Substance Abuse.