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Resident decision-making in the context of residential aged care

Evdokia Kalaitzidis, Ann Harrington*

School of Nursing and Midwifery Flinders University, Adelaide Australia

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ABSTRACT

Background: Worldwide research confirms that older people value autonomy, want to remain independent and want control over their lives for as long as possible. Accordingly, the aged care system in Australia is undergoing major government-initiated reforms and is moving towards consumer directed care.
Aim: To explore the views of residents and care staff of resident decision-making, choice and control in the residential aged care context.
Methods: Residents from across four residential aged care facilities in Adelaide were interviewed and staff focus groups were held. A thematic analysis of the data was conducted.
Findings: Residents valued opportunities for privacy, communal engagement, productivity, negotiation with staff, and for opportunities to engage with systems of governance. How staff prioritise resident decision-making is influenced by the carer's judgement of the resident's characteristics and of the organisation's rules and polices.
Discussion: Older people living in residential care are no longer living in their own home but instead are dealing with organisational rules and routines framed by others upon whom they are dependent.
Conclusion: The day-to-day decision-making process for residents is likely to remain complex due to residents having to take into account rules, regulations and policies operationalized through organisational channels.

Summary of relevance

Problem or issue

Little is known about how older people who are living in residential aged care, experience decision-making, choice and control.

What is already known?

Research confirms that older people want to remain independent, and to have control over their lives for as long as possible. Promoting independence, choice and control for older people is an aim of major government-initiated reforms in Australia, including consumer-directed care initiatives.

What this paper adds?

Evidence that in the context of residential care facilities, residents value opportunities for privacy, communal engagement, productivity, negotiation with staff, and for opportunities to engage with systems of governance.

1. Introduction and background

It has been shown that older people value autonomy, a quality related to having independence, choice and control (Cook, Thompson, & Reed, 2015; Petriwskyj, Gibson, & Webby, 2014). Research confirms that they want to remain independent, to be their own person and have control over their lives for as long as possible (Sikorska-Simmons, 2006; Stones & Gullifer, 2014). Autonomy and independence are not easily associated with the residential aged care context where the older person may wish to be autonomous, with assistance from others (Hillcoat-Nallétamby, 2014).

Pioneering research in 1975 suggests that the debilitating consequences of ageing, such as declining cognitive function, may be delayed in residents who make decisions (Langer & Rodin 1975). More recent research identifies other beneficial effects of decision-making including increased community participation (Boelsma, Baur Woelders, & Abma, 2014) and enhanced quality of life (Bradshaw, Playford, & Riazi 2012; Daatland & Hansen, 2007). Studies have found that policies fostering resident autonomy, choice and control have physical and psychological health benefits (Andersson, Pettersson, & Sidenvall, 2007; Chang, 2013).

As life expectancy rises, governments worldwide are considering their residential aged care policies (KPMG, 2014). Recent government policy developments include a shift affecting the care

* Corresponding author at: School of Nursing and Midwifery Flinders University, Bedford Park 5042, Adelaide, Australia.
E-mail address: Ann.Harrington@flinders.edu.au (A. Harrington).

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of older citizens in Australia from service-oriented approaches towards consumer-directed care (CDC) (Australian Government Department of Health. Ageing and Aged care, 2016). The aim of Consumer Directed Care is to provide and empower older citizens, as 'consumers', with choice and control over their lives to the types of services they access and the delivery of those services (Australian Government Department of Social Services, 2014).

In the context of Consumer Directed Care, the Australian Productivity Commission plays an important role. This Commission, underpinned by an Act of parliament, conducts independent research and is an advisory body on a range of social issues affecting the welfare of Australians. The recent Productivity Commission Report on Informed user choice (June 2017) argues that Consumer Directed Care principles apply in Residential Aged Care. Therefore individuals living in residential aged care facilities (RACFs) will also have greater opportunities for self-determination. On the basis of Consumer Directed Care, the aim of this study was to explore decision-making, choice and control from the perspective of residents in aged care and personal care workers.

1.1. Ethics

Ethical approval was gained from the university concerned and the RACFs involved prior to the implementation of the study

1.2. Research design

A qualitative exploratory design also called Interpretive Descriptive (Guba & Lincoln 1989) was employed. Qualitative research enables the study of things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Sarantakos, 2013). Interpretive Descrip*tion* research is a term coined by Thorne (2008) refers to 'a strategy for excavating, illuminating articulation and disseminating the kind of knowledge that disciplines with an application mandate need (2016 p.11)'. That is, within a practice based discipline that is nursing, its disciplinary epistemology directs its inquiry towards knowledge that can be of practical use (Thorne, Stephens, & Truant, 2015).

Thorne (2016) argues that this position is not 'atheoretical' rather the theoretical approach uses principles of qualitative research for applied disciplines such as 'education, community development, human geography and the health professions' (2016 p.11). She contends that the discipline of nursing requires a research method that is distinct from 'the more theoretically driven available social science knowledge development approaches' (2016 p.11). Given the practice focus of this project, Interpretive Description was an ideal lens through which to examine the interface between the practice of nursing and the aged care environment. The movement beyond traditional methodologies allows for the framing of research questions that better preserves 'disciplinary logic and methodological integrity' (Thorne et al., 2015 p.455). Data were collected from resident interviews and from staff focus groups. Within aged care facilities, issues of resident confidentiality need to be considered by researchers. Given the sensitive nature of the research topic and to maximise privacy and confidentiality of information, it was decided one on one interviews with residents would be the best approach. In contrast, the researchers chose a focus group approach with staff to obtain data that represented a collective rather than an individual view. As the research question was aimed at residents' views, the collective voice of the workforce via focus groups was used as a secondary source of data to highlight the context of care provision and to seek confirmation of that setting from more than one person.

In concert with Thorne's (2016) view of analysis of qualitative research, a manual thematic analysis of both sets of data was initially conducted by the Chief Investigator. This process consisted of the use of Morse (1994a in Thorne, 2016) scheme of 'cognitive processing': comprehending; synthesizing; theorizing; recontextualising the data then 'testing options' (working patterns and relationships within the data toward a more integrated conceptual claim and interpretation) (Thorne, 2016 pp184–185). Using these principles of qualitative thematic analysis, each member of the research team went through each of the scripts identifying patterns. The research team met on at least four occasions to compare, contrast and comprehend statements to test options until agreement was reached in regard to a final set of themes.

1.3. Study recruitment

Resident and care staff were sought from sites of two facilities. The RACFs in this study consisted of Independent Living Units, Single room accommodation and shared accommodation. The resident participants in this study resided in single room accommodation. The Chief Investigator attended one of the regular resident meetings at each RACF, and conducted a 'Research Information' session for potential resident participants. Information Sheets that included a small tear off section were made available to resident attendees. Residents were informed that if they wished to pass on their name and room number to the Chief Investigator they could do so by filling out the tear off section and placing it in a secure box located in the Resident's Common Room. For the care staff focus groups, management placed copies of recruitment flyers in staff room notice boards inviting interested personnel to contact the Chief Investigator. Prior to recruitment the process of informed consent was undertaken with each resident who indicated interest in the study. Informed Consent included the explanation of the study, risks associated, capacity to withdraw, confidentiality and anonymity. During this procedure there were no identified deficits in the cognition of any resident ensuring that each potential participant had cognitive capacity. The researchers had set an inclusion criteria for residents with intact cognitive capacity that identified they would be able to process information. Those residents who had capacity and who were proficient in English expression were eligible for inclusion in the study. Potential resident participants were invited to contact the Chief Investigator for further information about the study. In total, 18 residents were recruited. An audio-recorded one-on-one semi-structured interview was conducted by the Chief Investigator with 18 residents. Pre-determined questions developed by the researchers were posed to residents and included "*Can you describe your decision-making experiences before, and since you became a resident in an Residential Aged Care Facility*?"

Two audio-recorded focus groups of care staff that provide direct resident care were also conducted by the Chief Investigator, one for care staff from each of the two aged care facilities. To maximise a safe environment for focus group participants the Chief Investigator informed at the outset that all attendees were care workers of the same status. That is, there were no senior personnel present and each participant's response was valued. Further, when consent was obtained, all agreed to participate in the focus group, aware of others who were present. The researchers developed questions to guide the focus group discussion. For example "*Would you comment on your role and function in the organization?*". A research assistant was present at each focus group to assist in the overall management of the session. For example they set up the recording equipment, organised refreshments and monitored entry into the room. A total of eight attended the focus groups, three from one facility and five from the other.

Interview and focus group data was transcribed independently by a Professional Transcriber. While the anonymity of resident participants was ensured by decoding identifying data, the anonymity