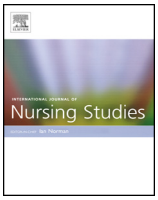
International Journal of Nursing Studies 96 (2019) 44–52

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns



The acute care experience of older persons with cognitive impairment and their families: A qualitative study

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ARTICLE INFO

Keywords:
Acute care
Dementia
Family carers
Mild cognitive impairment
Older persons
Qualitative research
Quality of care
Person-centeredness

ABSTRACT

Background: An increase in older persons with pre-existing cognitive impairment requiring inpatient services for co-occurring acute illness has produced a need for acute care processes to be re-designed. This in particular as this patient group is at risk of receiving insufficient care, resulting in adverse health and functional outcomes as well as family burden. Thus, to improve and sustain quality care over time, there is a need for an in-depth understanding of acute care processes from the perspective of persons with cognitive impairment and their families.

Objectives: To generate an in-depth understanding of the experiences of acute care processes and the needs of older, hospitalized, older persons with cognitive impairment and their family members.

Design: A qualitative study using inductive content analysis.

Setting and participants: The study was conducted at two urban, university-affiliated tertiary care hospitals in Switzerland. Eighteen families, represented by seven older persons with cognitive impairment and 20 family members were recruited into the study from six units.

Methods: Semi-structured, narrative individual or dyadic interviews (n = 19) were conducted over a six-month period in 2017. The interview data were analyzed using inductive content analysis strategies.

Results: Persons with cognitive impairment and their families described a wide range of acute care experiences that oscillated between supportive and unsupportive, comprehensive and fragmented, as well as proactive family engagement and none. Seven core dimensions were identified as constituting the acute care experience from participants' perspective. In relation to care for persons with cognitive impairment, caring attentiveness and responsiveness were important, whereas family members valued access to staff and information, participation in care, and support over time. On a system level, available resources and the hospital infrastructure were integral to their experience of hospitalisation.

Conclusions: Participants gave manifold examples of good care. However, they reported that their specific needs and preferences were not always identified or met. Family members understood themselves as integral to the well-being of their hospitalized older member with cognitive impairment. Therefore, they need to be recognized and involved in acute care processes, and supported in their caregiving. The study shows the need and ways to move towards person- and family-centered models of care. System-wide initiatives that translate knowledge into practice and ensure a skilled workforce with sufficient resources are called for.

What is already known about the topic?

- Older persons with cognitive impairment who require acute care are at risk for adverse health outcomes such as cognitive and functional decline.
- In acute care settings, older person with cognitive impairment's and their family members' complex and specific care needs are insufficiently met.

What this paper adds

- Based on participants' narrations and descriptions, this study delineates seven core dimensions that constitute the acute care experience for older persons with cognitive impairment and family members.

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https://doi.org/10.1016/j.ijnurstu.2018.11.008
0020-7489/

- Findings reveal that participants experience high variation in acute care processes, both across and within cases and hospitalization episodes, which suggests that while pockets of quality care exist, there is a need to move towards more consistent delivery of person and family-centred care processes.

1. Introduction

In acute care settings, the increase in older persons with pre-existing cognitive impairment requiring inpatient services for co-occurring acute illness has produced a need for care processes and hospital environments to be re-designed. Ranging from mild to severe, cognitive impairment is characterized by memory problems, difficulties with learning new things, concentrating, making decisions in everyday life, and by personality and behavioral changes (Centers for Disease Control and Prevention, 2011). Research reports that up to 40% of older persons admitted to acute care settings have some form of cognitive impairment (Mukadam and Sampson, 2011; Reynish et al., 2017), and it is likely that many more older persons are admitted with undiagnosed or unrecognized cognitive impairment (Jackson et al., 2017). Dementia prevalence has been found to range between 15% to 40%, with almost 10% of acute care bed days attributable to persons with dementia (Briggs et al., 2016; Zekry et al., 2009).

Persons with cognitive impairment in acute care hospitals are usually admitted in crisis (Jackson et al., 2017), and are at high risks for adverse health outcomes, such as superimposed delirium, falls, functional decline, malnutrition, and death (Fogg et al., 2018; Reynish et al., 2017; Sheehan et al., 2013), as well as higher cost of care and repeat admission (Bail et al., 2015; Daiello et al., 2014). Acute care provision to older persons is very complex due to prevalent multi-morbidity as well as age-related physiological and functional changes, in particular when cognitive impairment co-exists (Fedarko, 2011; Weiss, 2011). Persons with cognitive impairment not only have physical, but along with their families, have particular emotional, social and spiritual care needs also warranting attention. It is vital that they encounter an environment that allows interaction with family or friends and provides safety as well as limited stimulation (Baumbusch et al., 2016). However, the acute care context is inherently incompatible with the care needs of older persons with cognitive impairment and their families (Borbasi et al., 2006; Bridges et al., 2010; Edvardsson and Nay, 2009). Hospitals prioritize acute intervention models (Baumbusch et al., 2016), and efficiency in moving patients as swiftly as possible through the system. Physical environments are often monotonous and confusing. They offer limited space for social interaction or opportunities to move around freely and safely (Baillie et al., 2012; Calnan et al., 2013; Parke et al., 2017). Accordingly, care frequently fails to meet the unique health care needs of this population. Individuality and personhood are not honored, especially when verbal communication is not possible (Clissett et al., 2013a; Gaugler and Wocken, 2014). Involving family members in care processes and decision-making is perceived as an additional burden (Whittamore et al., 2014). This lack of quality care leads to increased complications, prolonged length of stay and caregiver burden (Chen et al., 2011; Covinsky et al., 2011; Soto et al., 2012).

Research investigating the perspective of persons with dementia and other forms of cognitive impairment and their families reflects the current state of acute care for this population. Family members report feelings of burden and unmet needs regarding information sharing, individualized caring, relationship with staff, and discharge management (Nufer and Spichiger, 2011). Not being involved in decisions about care or not being recognized for their own care experiences are also consistently reported (Bridges et al., 2010; Higgins et al., 2007; Küttel et al., 2015). Persons with cognitive impairment themselves report feelings of being worthless, fearful, lonely and not in control of what is going on (Clissett et al., 2013a; Cowdell, 2010; Stenwall et al., 2008). While most studies have focused exclusively on patients with dementia, current international guidelines for acute care settings address all persons with cognitive impairment (Naef et al., 2018). They clarify possible components of care, such as systematic screening, interventions to sustain personhood, involvement of family members, physical environment modification, multi-professional team work, and the development of care pathways (Australian Commission on Safety and Quality in Health Care, 2014; Registered Nurses Association of Ontario, 2016; Swiss Academy of Medical Sciences, 2017). Before best practice can be implemented to improve and sustain quality of care over time, there must be an in-depth understanding of the specific needs, practices and challenges of those involved in delivering and receiving care within the local context where such interventions will be introduced. While most research has focused on persons with dementia, many older persons admitted to acute care who present with cognitive impairment have not, or not yet been formally diagnosed (Jackson et al., 2017). As such, it is essential to be inclusive of many different forms of cognitive impairment. Therefore, the aim of this qualitative study was twofold: First, to explore how persons with some form of cognitive impairment experience acute care processes and settings together with their family members, and second, to ascertain their care needs in relation to the hospital stay.

2. Methods

2.1. Study design

This qualitative study is part of a mixed-methods project aiming to develop a base for improving the experience of acute care delivery for persons with cognitive impairments, their family members, and health professionals alike. A qualitative methodology is best suited to gain insights through people's real-life descriptions and narrations, while considering the experiences as embedded in and as formed by concrete social contexts, such as acute care settings (Creswell, 2013). A qualitative design with inductive analytical strategies was used because it allows to focus on the particular and contextual while abstracting data in such a way that it captures both similarities and differences present in the data (Graneheim et al., 2017).

2.2. Setting and participants

The study took place in two urban, university-affiliated tertiary care hospitals in Switzerland. A convenient sample of older persons (>65 years) with cognitive impairment admitted between May and October 2017, and/or their family member(s) was recruited into the study by clinical nurse specialists (n = 3) working on the six study units (n = 4 geriatric wards, n = 2 general internal medicine wards). Those eligible were older persons with a diagnosis of dementia, mild cognitive impairment or those who presented with self-reported or nurse-observed cognitive impairment. Excluded were older persons with delirium or severe hearing limitation. At least one family member or someone close as indicated by the older, hospitalized person, or as designated in the patient record was invited to partake in the study. Participants had to be cognitively able to understand the study, to sign an informed consent form, and to take part in an interview in German, either alone or with a family member. Families' reason for declining participation included lack of time due to caregiving burden.

The decision regarding sample size was guided by considerations around the heterogeneity of the sample, the completeness of data in relation to each case, and redundancy of themes present in the data (Baker and Edwards, 2012). A sample size of 15–20 cases, represented by family members and, if possible, persons with cognitive impairment, was considered sufficient to answer the research question.

2.3. Data collection

Nineteen semi-structured, narrative interviews were conducted by the last author who did not know the participants. If possible, dyadic interviews were held, as they allow the researcher to discern how families experience acute care processes together while at the same time learning about their individual experiences (Feetham, 2018). To capture the entire hospital experience, interviews were carried out after discharge, either at home, an institutional care setting, or other. A semi-structured, narrative interview form was used to invite participants to talk about their experiences of acute care. Rather than asking only for reflections on past experiences and needs, a narrative description of actions and situations was sought to understand individuals' experiences through concrete examples of everyday hospital care (Kesselring et al., 2009; Kvale and Brinkmann, 2009). While an interview guide was used, there was no fixed order of the questions to be asked. Participants were invited to talk about the events leading up to the hospitalization, their experience of receiving care, and to give concrete, narrative examples of the care they received and how care met or did not meet their needs. Questions included: "What was important to you while in the hospital?" "What was particularly helpful or difficult for you?" Could you describe a situation in which you felt that you received the best possible care." "Could you now please tell me about an instance in which you felt left alone or not well cared for?" Interviews were held in German and lasted on average 37 (13–87) min. They were audio-recorded, transcribed verbatim and anonymized transcripts entered into Atlas.ti version 5 for data management purposes and to assist analysis.

Field notes were written immediately after the interview and included observations, reflections on participants' descriptions and the researcher's role. Medical information was retrieved from the patient record. Demographic information from persons with cognitive impairment and family members was collected using a short questionnaire.

2.4. Data analysis

The unit of analysis were families. Data was analyzed inductively using content analysis strategies (Elo and Kyngas, 2008; Graneheim and Lundman, 2004). An inductive content analysis approach is characterized by a search for patterns as the researcher moves from the concrete to the abstract and from parts to the whole of the text (Graneheim et al., 2017). First, each interview transcript was read and re-read by two researchers to become familiar with the data as a whole. To make sense of the data, preliminary ideas were captured in interpretive notes and discussed in an interpretive team meeting. Next, sentences and paragraphs that carried meaning in relation to the research questions were identified and inductively coded by one researcher. In a second meeting, the codes were compared based on differences and similarities and sorted into emerging categories. Data, that is, raw text was then reviewed according to these emerging categories, read again, and further sorted into overarching themes. Interpretive writing on the ascertained themes refined its structure and interrelationships, which were displayed in a conceptual map. Lastly, the thematic findings structure with its categories was described and illustrated with quotes.

2.5. Trustworthiness

To establish trustworthiness, several strategies were used based on the criteria of Elo et al. (2014), including a thorough preparation of the study, careful data gathering, availability of rich and well-saturated data, transparent analysis involving two researchers with training and experience in qualitative methodology, and a congruent, clear, and conceptual presentation of the data with systematic use of quotes to contextualize interpretations (Graneheim et al., 2017). To ensure credibility, an audit trail (analytical notes, meeting reports) was created, and field notes were written to capture participants' context and the researcher-participant interaction.

2.6. Ethical considerations

The study was approved by the Ethics Committee of Canton Zurich and was conducted according to the Swiss law and national guideline of Research on Humans in Health and Illness (Swiss Academy of Medical Sciences, 2015). Due to the high vulnerability

Table 1
Participant and interview characteristics.

Characteristics	Family members (n = 20)	Older persons (n = 7)
Age, median (min-max)	63 (51–80)	86 (70–98)
Male gender, n (%)	6 (30)	3 (42.9)
Living situation, n (%)		
alone	3 (15)	4 (57.1)
with spouse or family	17 (85)	3 (42.9)
Lives with older person, n (%)	7 (35)	–
Relationship to older person, n (%)		
spouse	7 (35)	–
adult child	10 (50)	–
daughter/son-in-law	2 (10)	–
neighbour	1 (5)	–
Is the primary caregiver, n (%)	17 (85)	–
Is supported by professional care, n (%)	16 (80)	–
Self-perceived health status, n (%)		
excellent	3 (15)	–
good	9 (45)	–
neither good nor poor	6 (30)	–
poor	2 (10)	–
Participation in dyadic interview, n (%)	10 (50%)	6 (86%)
Interview at post-discharge day, median (min-max)	10 (1–42)	6 (0–42)

of older persons with cognitive impairment, utmost care was necessary during recruitment and data collection. Nurses who recruited participants first discerned persons' ability to participate before inviting older persons into the study. They reviewed the available cognitive assessment and consulted with primary nurse and/or with family members. Older persons were informed about the study and invited to take part face-to-face, whereas family members were also contacted by phone. Once potential participants expressed interest in participation, the researcher contacted the older person and / or family member by phone, or if possible, in person, to explain the study, answer questions, and provide written study information. Written informed consent was obtained from each person prior to conducting the interviews. All but one older person were interviewed with a family member. If older persons' ability to participate could not be clearly established or doubts remained, they were not included in the study.

3. Findings

3.1. Participant characteristics

Eighteen families represented by 27 individuals took part in the study (Table 1). Family members included adult children (n = 11, median age 62, 51–68 years), spouses/partners (n = 6, median age 76, 71–80 years), in-laws (n = 2, 57 and 61 years), and one neighbour (70 years). Persons with cognitive impairment had a median age of 86 (70–98) years and lived with mild cognitive impairment (n = 3) or mild to moderate dementia (n = 4). In those families in which the older person was unable to take part, all had been diagnosed with dementia and had a median age of 83 (73–93) years. Falls were the main cause for admission. Six older persons underwent surgery, predominantly for fall-related fractures. All except one older person were cared for on a specialized geriatric ward for at least part of their hospitalization. Further characteristics of older persons are displayed in Table 2.

3.2. Acute care experience

Findings revealed that older persons with cognitive impairment and their family members experienced considerable variation in their experience of acute care, even within the same hospitalization and illness episode. Their experience ranged from one that was supportive of individual and family needs and comprehensively delivered, to one that failed to address needs, occurred fragmented, and lacked family involvement. Despite the fact that participants reported a broad range of care experiences, data revealed seven core dimensions inherent to their acute care experience, which gave rise to corresponding care needs (Table 3). Participants' experience of care was constituted by the degree to which these core dimensions were addressed and corresponding needs met, or failed to be addressed and met. Core dimensions and needs elicited pertain to the tripod of dementia care (Hannan et al., 2013); that is, to the care provided to older persons with cognitive impairment, the involvement and support of family members, and the acute care context, including staff and system issues.

3.2.1. Older person with cognitive impairment

Participants' experience of acute care was constituted by staff's caring attentiveness and responsiveness towards the older person with cognitive impairment and their care needs. Older persons and family members vividly described the ways that good care was present or absent for them. Their experience of and trust in good care developed, or failed to develop, depending on participants' interactions with staff and/or observations of care.

3.2.1.1. Caring attentiveness – being acknowledged as a person. Caring attentiveness was embedded in interpersonal interactions with the person with cognitive impairment. All participants portrayed health professionals as *being kind and nice*, and taking an interest in the older person as an individual, as the following daughter-mother interaction illustrates "*They are very communicative and very //Older person: yes open// and empathetic – that surprised me positively. They certainly have enough patients and it is an acute care hospital. I was surprised //Older person: Yes, not just a number// No, no, and they explained things, if you received a new medication, the physician first talked to you, very much on eye-level" (family member / older person 10).* Characteristics attributed to health professionals included being *flexible, warm-hearted, thoughtful, patient, competent, helpful,* and *reliable.* For

Table 2
Older persons' admission and discharge characteristics.

Characteristics	Patients (n = 18)
Pre-existing dementia diagnosis, n (%)	7 (38.9)
Mini-Mental State Examination upon admission, n = 16, median (min–max)	19 (10–27)
Cause of admission, n = 17, n (%)	
Fall	9 (52.9)
Confusional state/dehydration	5 (29.4)
Infection/Pneumonia	2 (11.7)
Other	1 (5.9)
Admission from, n = 17, n (%)	
Own home	9 (52.9)
Long-term care	2 (11.8)
Transitional care	1 (5.9)
Other hospital	1 (5.9)
Other ward in same hospital	4 (23.5)
Number of medication(s) upon admission, median (min–max)	5 (1–17)
Delirium during hospitalization, n (%)	6 (33.3)
Length of stay (days), median (min-max)	17 (5–30)
Diagnosis at discharge, n (%)	
Dementia	15 (83.3)
Mild cognitive impairment	3 (16.7)
Number of medication at discharge, median (min–max)	6 (3–14)
Discharge to, n (%)	
Own home	5 (27.8)
Long-term care	4 (22.2)
Transitional care	7 (38.9)
Other hospital	2 (11.1)
Change in living situation, n (%)	6 (33.3)

Table 3
Findings structure.

Tripod of care	Core dimensions of acute care experience and care needs
Older persons with cognitive impairment	Caring attentiveness – Being known as a person
	Responsiveness – Being well looked after
Family members	Access to staff - Receiving continuous and timely information
	Participation in care - Being recognized and involved
	Support over time - Receiving education and counselling
Staff and system	Staff and time resources - Having adequate resources
	Hospital infrastructure - Encountering a supportive environment

older persons, being acknowledged as a person was important, as one participant explained: *"They recognized me immediately (from a previous hospitalization) and were very kind, they did what they could for me (older person 02).*

However, some participants reported encounters that lacked such attributes of caring attentiveness, as one family member explained about a nurse: *"She came in, no hello, no good-bye, she said nothing" (family member 08).* Such encounters instilled doubts about health professionals' aptitude for the profession, but also about staff's empathy in caring for persons with cognitive impairment: *"They apply good dressings, personal hygiene is all is very good, really, nothing to complain there. They do their job, but nothing more. The humane, the extra mile you could go, that's more difficult" (family member 05).* Concerns around a lack of caring attentiveness arose when family members gained the impression that their hospitalized older family member was not well looked after: "*I think they do not look after her (. . .). When I visited, she was mostly in bed in her nightgown. Whenever I came, she was always in bed (family member 07).* In contrast, seeing staff being present reassured family members: "*I just knew that she was in good hands" (family member 06).* Caring attentiveness was a practice through which persons with cognitive impairment felt acknowledged and valued, and family members reassured – or concerned about the care provided to their hospitalized family member, as participants experienced or observed instances in which older person's personhood was not fully honored.

3.2.1.2. Responsiveness – being well looked after. The availability of staff to support persons with cognitive impairment in their activities of daily living was an essential caring practice described and appreciated by participants: *"You need people around you whom you can trust, who support you. The hospital was like that, there was always someone asking how I was doing" (older person 11).* The fact that there was always someone around to help promptly was highly appreciated, as one older woman noted: "*Someone came right away when I needed something" (older person 10).* The extent to which older persons' needs were recognized and responded to was pivotal to participants' acute care experience. In the acute care context, family members perceived their hospitalized close other to be vulnerable due to their cognitive impairment: *"My husband has great difficulties to express himself, which is a problem, also for others" (family member 09).* Older persons tried to fit in and be inconspicuous, as one older women explained: "*Well, I complied and did what they wanted. I am a bit old fashioned that way (older person 02).* Thus, family members were concerned about the extent to which their older relatives' could voice their needs, and the extent to which they were recognized and met. Some observed that needs pertaining to eating, drinking, physical well-being, personal hygiene, activity and occupation, remained unmet: *"They do not pay enough attention to basic needs. Nurses tell him to drink more but don't make sure that he really does" (family member 09).* Persons with cognitive impairment felt lost and bored at the hospital, as one spouse illustrated; "*He constantly called me up to ask where his things were (. . .). When he was in therapy, things were quiet, and he was well, but when he was back in his room, alone, he (told me): 'I am fed up, I want to come home, I am bored and nothing happens'» (family member 08).* While some were able to read or watch television, others could not structure their days. Scheduled therapy sessions were appreciated, but insufficient. Many family members felt that meaningful occupation and activation was lacking, whereas others felt that the older persons' needs were met.

3.2.2. Family members

Family member experienced a varying degree of engagement and support. Some family members' needs were met: *"I felt immediately at ease. Staff approached me, and when I had questions, I didn't have to wait for hours until they got back to me" (family member 13).* Others encountered little interest from staff, which meant that their concerns, questions, and support needs were overlooked: *"I didn't have any interaction (with staff). Sometimes, when you were visiting, you didn't see a soul" (family member 01).* Common to all care situations was families' need for access to staff and information, participation in care, and support as a family over time.

3.2.2.1. Access to staff– receiving continuous and timely information. Access to staff and information was not always easy for family members to negotiate. Challenges included reaching the nurse and physician who were in charge and knowledgeable about the person with cognitive impairment's situation and plan of care, and receiving answers to questions: *"It took great effort (to find out) who is in charge, but after that you could ask for that person" (family member 04*). Establishing a line of communication with health professionals was important for family members, as illustrated by the following: *"I need (the line of communication) so that I dare to ask questions and don't feel like an idiot. I called the ward every morning and always received competent information*" *(family member 06).* However, some family members' questions were not answered: *"They gave me the runaround. It was a simple question I asked, but I did not get an answer" (family member 07*). Receiving inadequate or insufficient information left family members upset. One son needed four days to get through to a health professional in charge of his mother's care: *"From a human perspective, this is unacceptable. Wouldn't you expect that if your family member is in the hospital you need to know what is going on? I felt very helpless and angry about the poor way I was informed" (family member 17).* Partly, family members did not mind to proactively contacting health professionals to seek information if access was guaranteed: *"As long as people can tell me when the physician is available. 'If you call at 11.30* a.m. *tomorrow, he will have finished his rounds and will know best what the (status is)', that is sufficient for me. I find it is my responsibility to actively seek the information I need, that is just normal to me*" *(family member 14).* Others felt more like an intruder and did not take such a proactive stance. Some families felt well informed, while others lacked continuous interaction with a nurse and/or physician responsible for the care of their relative: "*For me the hospital should have a face and a name. I don't want to talk to ten physicians and ten nurses. I would like to know who my contact person is" (family member 05).* Working family members had more difficulty accessing health professionals and receiving necessary information than those who could be present during the day. Having access to health professionals when needed and having continuous, timely information face-to-face, by phone or email, was family members′ most important need.

3.2.2.2. Participation in care – being recognized and involved. Participating family members wanted to play an active caring role. When family members were actively contacted and/or involved by a health care professional to discuss care plans or to tap into their knowledge about the family member, they felt acknowledged as important others whose lives were also affected by the situation: *"The most I have felt being taken seriously was during a phone call with the leading physician after they performed the first tests. He contacted me and asked about how I had perceived my mother in daily life. That was absolutely great" (family member 16).* When staff valued the presence of family and expressed this by offering coffee or food, for instance, they felt welcomed and appreciated. Proactive involvement by staff occurred most often regarding discharge planning and newly diagnosed dementia. Staff contacted family members to plan discharge and follow-up care if needed or a round-table meeting with the health care team to discuss test results. Mostly, this active participation was invited only at one point, which was insufficient: *"Well, there was absolutely no feedback from health professionals during the process. Like, 'we perceive your mother like this, or we feel she is anxious or . . . '. That was missing. It would have been nice if someone had once said: 'Do you have a moment? 'Look, Mr. X, this is the current situation . . . '" (family member 16).* Not all family members were involved in the care process despite being present. Lack of involvement in the care process or unprepared involvement left family members upset and feeling disregarded. In contrast, they felt acknowledged as important others when they were welcomed, listened to, and consulted on the wardd.

3.2.2.3. Support over time– receiving education and counseling. Family members' support needs pertained to information, emotional, educational, and counselling needs. Information needs – as illustrated – were sometimes met and sometimes not. While some family members did not look for emotional comfort, others appreciated the emotional support they received. One daughter stated: *"The first days were emotionally very difficult. The nurses communicated that I don't have to feel ashamed about it. They had a sense for it" (family member 06).* Moreover, family members had educational and counseling needs in relation to the post-hospitalization phase, particularly when the acute illness brought about changes in health and living situations. One spouse, whose husband had a hip replacement, was in need of instructions: "*I have no clue about care, how I can help my husband or get up and such. Nobody told me anything. Family members should be involved more so that they know what to expect. And that someone gives me instructions" (family member 09).* Therefore, family members often felt ill-prepared for the post-acute period and left alone in important decision-making processes regarding living arrangements and community support. One family described the challenge as follows: *"Decision-making is very difficult in a situation like that. What am I going to do with the apartment? That is his life, his world. What is the right decision? Where is this whole thing going? What do I have to prepare for?" (family member 05).*

3.2.3. Staff and system

The nature of the acute care setting played an important role in participants' care experiences. Family members in particular made multiple references to system issues promoting or impeding their experience of good care, and enabling or hindering staff from meeting the care needs of their vulnerable older relative. In the interviews, descriptions of care experiences and interactions with staff were contained in reflections on available resources, hospital environments, and the wider health care system.

3.2.3.1. Staff and time resources – having adequate resources. Persons with cognitive impairment and family members, when describing inadequate or unsatisfactory care, acknowledged that it was the best possible care, given staffing and / or time resources: *"They don't have time. But when asked, they come immediately. He is someone who never asks for anything . . . However, I would like to emphasize, the staff was good!" (family member 11).* Family members acknowledged the time pressure but also saw the risk of inadequate care. They expressed having high regard for health professionals' willingness to engage in care work: *"Well, it is really nice how people make the effort. I have a lot of respect" (family member 14).* However, they made their priorities clear: *"I have no idea how much administrative work awaits them beyond direct patient care. For me, it is important that first and foremost, they make sure that patients get what they need" (family member 06).* Family members questioned the amount of time spent on documentation and administration processes. They could not understand the lack of care quality when they saw how many staff members were on duty. Overall, while family members understood the financial pressure that staff and hospitals were under, they nonetheless expected the hospital to support staff in meeting the needs of persons with cognitive impairment.

3.2.3.2. Hospital infrastructure – encountering a supportive environment. The hospital environment is another core dimension of participants' acute care experience, specifically the patient room and the infrastructure on the ward. Some mentioned the absence of a private bathroom and ongoing construction (noise), while others appreciated the great view, the access to an outdoor garden or terrace or acknowledged recent refurbishment to increase comfort. Characteristics of the patient room such as size, temperature, access to a terrace and cleanliness were also important. Orientation within the hospital was a challenge, not just for persons with cognitive impairment. Technical equipment, such as TV, radio or phone were often too complicated for use by persons with cognitive impairment. Food was a very important aspect of care quality. Sharing a room with other patients either increased the hospitalization experience (fun, sociality) or made it more difficult, but most put up with it, as one older person explained: *"I would have preferred (a private room), of course, that's for sure, but that is how it is, a fact, right. Then I picture the old times, with those large patient halls" (older person 10).* While older persons with cognitive impairment and family members alike hoped for a supportive environment, they acknowledged the limitations inherent in the building structure, and dealt with the adversities encountered.

4. Discussion

This study reveals that older persons with dementia or other forms of cognitive impairment and their families entering and moving through hospital inpatient settings encounter very different levels of person- and family-centeredness. While many participants experienced what they considered good care, others encountered a lack of understanding of cognitive impairment itself and its impact on care needs. From family members' point of view, there was insufficient activation and skilled management of challenging behaviors, and an absence of integrated care processes. In a similar vein, other studies have found that the acute care processes for this patient group are fraught with inconsistencies (Clissett et al., 2013b,2014; Nufer and Spichiger, 2011). Often, current recommendations for good practice are not assured consistently across the inpatient services that persons with cognitive impairment access (Cowdell, 2010; Innes et al., 2016). Along with other research involving family members of cognitively impaired persons (Clissett et al., 2013a; Moyle et al., 2016), this study indicates that family members want to be part of the acute care process. Nonetheless, family members encountered considerable discrepancies in the care and support they and the persons with cognitive impairment received. A meta-synthesis found, as did this study, that although family members report positive care experiences, they often face a “cycle of negative feelings” due to their worries and unmet needs, adding emotional stress to an already burdensome situation (Burgstaller et al., 2018; Jurgens et al., 2012). Even though participants in this study experienced person-centered *moments*, they did not encounter an acute care system permeated with a person- and family-centered *culture* (McCormack et al., 2011).

Despite this considerable variation within and across cases, seven core dimensions emerged from participants' descriptions and narrations that – in their absence or presence – constitute their acute care experience. As such, we posit that they are indicators of good care from the perspective of persons with cognitive impairment and family members, which give rise to particular acute care needs. For older persons who participated in the study, it was important to be recognized as a person and to be well looked after. This is consistent with other research that found that persons with cognitive impairment desire that hospital staff spend time with them and attend to their needs with a human touch (Hynninen et al., 2015; Scerri et al., 2015). Since Kitwood's (1993) introduction of person-centered dementia care, sustaining personhood in individuals has been a core concept in recommendations (Australian Commission on Safety and Quality in Health Care, 2014; Royal College of Nursing, 2013). Research shows that hospital staff often does not honor older persons with cognitive impairment's personhood (Clissett et al., 2013a; Hynninen et al., 2015). In contrast, older persons in this study reported individualized, attentive care. In interpreting these findings, the small number of older persons in this study needs to be taken into account.

For family members, having access to staff and information, being recognized as an important other, experiencing involvement in care processes, and receiving support was at the core of their acute care experience. It is no surprise that having access to health professionals when needed and having continuous, timely information was family members' most important need, particularly in light of their ill family member's cognitive limitation. A systematic review suggested that better communication between patients and care providers translates into better clinical outcomes (Griffin et al., 2004). Other surveys also identified communication with nurses and physicians as the most important domain correlating to overall patient satisfaction (Mohammed et al., 2016). In the event of a limitation or inability of patients to communicate, family members are proxy recipients of information (Moyle et al., 2016). However, as family members in this study were not always involved from the start and in a proactive manner in the acute care processes, they had to take on the extra work of negotiating access and participation in care and decision-making processes, adding to their burden of care (Jurgens et al., 2012). Lack of attention to family members' importance, and need to be involved and partnered with, has also been reported elsewhere (Burgstaller et al., 2018; Clissett et al., 2013b; Digby et al., 2017).

This study further reveals that family members require understanding and support during the acute illness situation and beyond (Naef et al., 2018). In this study, support needs included the recognition of and attention to families' concerns and families' caregiving responsibilities. Educational needs pertained to disease management processes, expected illness trajectory, its implications for daily functioning, and available community resources. Counseling needs arose in relation to the changed health and functional status, but also to family processes, including substitute decision-making and the negotiating of caregiving – care receiving. Research has demonstrated that partnering with and supporting family members of older persons with cognitive impairment increases their satisfaction with hospital care (Goldberg et al., 2013) and preparedness for caregiving, and impacts positively on their level of anxiety and depression (Boltz et al., 2014).

Finally, available resources and the hospital infrastructure influenced participants' care experience. They were aware of the chasm that exists between the acute care focus and their care needs, and they acknowledged the efforts that health professionals made despite a lack of time and staff resources. Research with hospital staff mirrors participants' perception of contextual constraints inhibiting the translation of good practice in dementia and family care into hospital settings (Baumbusch et al., 2016; Houghton et al., 2016; Scerri et al., 2015). While participants considered care to be more important, the hospital environment, including interior decoration in patient rooms and their size, access to nature and the outside, and the amount of noise also mattered (Digby and Bloomer, 2014; Digby et al., 2016). In this study, it became evident that the environment and the equipment available was not always suitable and usable for persons with cognitive impairment (Parke et al., 2017).

4.1. Limitations and strengths

We were able to include 18 families, but only seven older persons with cognitive impairment took part. While this study attempted to include persons with mild cognitive impairment and dementia, it is likely that the voices of those with more advanced forms of cognitive impairment, who are at high risk for poor care experiences, are not, or only indirectly represented in this study. In 11 instances, we had to rely on family member-reported experiences of acute care. Moreover, the perspective of older persons with cognitive impairment who did not have family available or willing to take part in the study were not included due to ethical concerns around informed consent. Thus, issues of representation, together with the small sample size of included older persons, denotes a limitation to this study.

Among family members, about half were adult children, followed by spouses. Given that more women than men carry out family caregiving, it is not surprising that the majority of participants were women. However, a sample size of 18 cases may not have been large enough to capture the full variance of families; that is, older persons' and their close others' needs and experiences of acute care. While the inclusion of 20 family members allowed for redundancy of themes despite some heterogeneity in family and caregiving situations, completeness of themes was only partially achieved. Nonetheless, the amount of data generated through 19 interviews with 18 families, recruited from two hospitals, allowed for seven common themes to be discerned from family participants' description of their acute care experiences. Data was gathered by experienced researchers, analyzed using a stringent and transparent process that included regular interpretive team. While the study findings echo research knowledge from other countries, when transferring results, the local and cultural context in which the study took place needs to be taken into account.

5. Conclusions

The study findings imply that efforts to increase care quality for persons with cognitive impairment and their families in acute care settings require a multi-level approach, including attention to hospital infrastructure and resources, models of family-centered, dementia-specific, geriatric models of care, and coordinated care pathways that ensure consistency and integration of care from patients and families' perspective (Naef et al., 2018). This qualitative study with its seven core dimensions of acute care experiences, derived from participants' descriptions and narrations, provides a context-specific, databased foundation upon which inpatient care processes for this vulnerable group can be developed, implemented, and evaluated.

Participants gave manifold examples of good care. However, there is room for improvement, which mirrors findings around acute care processes from different countries. In particular, understanding and meeting the specific care needs associated with cognitive impairment and engaging families proactively over time is needed both on general as well as on specialized units. System-wide efforts to translate existing knowledge into clinical actions are called for (Phillipson et al., 2016). Person- and family-centered dementia care in acute settings has been explored in depth (Australian Commission on Safety and Quality in Health Care, 2014; Royal College of Nursing, 2013). However, as evidenced in this study as well as others, its adoption remains incomplete. Families require both relational and psycho-educational interventions that strengthen their relationships, enable family caring, create supportive environments, and promote their well-being (Chesla, 2010; Martire, 2005; Östlund and Persson, 2014). Hospitals need to ensure that sufficient resources are allocated, provide a consistent approach to care, and empower staff, both in terms of knowledge translation but also in relation to skills in geriatric, dementia and family care. While the qualitative evidence base regarding acute care experiences and needs is growing, there is a need for research that differentiates between subgroups, for instance in relation to cognitive and functional limitations and extent of family caregiving. Research that allows for the voices of persons with dementia and more advanced forms of cognitive impairment to be heard, is also called for. Moreover, we need to better understand how the quality of acute care processes affect clinical outcomes. Research that tests new models of care or care pathways is also needed in order to learn about how knowledge is translated into practice and consequently into better clinical outcomes for persons with cognitive impairment and their families. Lastly, the needs of and risks encountered by an ever-increasing number of older persons with cognitive impairment requiring inpatient care for co-occurring acute illness calls for attention at local and national policy levels in order to guarantee that the healthcare system has sufficient resources to ensure good practice.

Funding

This work was funded by the Swiss Alzheimer Association.

Acknowledgement

We would like to thank Esther Stadelmann for her support in recruiting participants for this study.

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