

Article



Exploring the perceptions of people with dementia about the social robot PARO in a hospital setting

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Abstract

New technology, such as social robots, opens up new opportunities in hospital settings. PARO, a robotic pet seal, was designed to provide emotional and social support for older people with dementia. We applied video-ethnographic methods, including conversational interviews and observations with video recording among 10 patient participants while they were using the robot. We also conducted semi-structured individual interviews and focus groups with nursing staff to gain contextual information. Patient and family partners were actively involved in the study as coresearchers. This study reports our findings on the perceptions of 10 patients with dementia about their experiences with PARO in a hospital setting. Thematic analysis yielded three substantive themes: (a) 'it's like a buddy' – the robot helps people with dementia uphold a sense of self in the world, (b) 'it's a conversation piece' – the baby seal facilitates social connection and (c) 'it makes me happy' – PARO transforms and humanizes the clinical setting. Our findings help provide a better understanding of the perspectives of patients with dementia on the use of social robots.

Keywords

dementia, patient experience, person-centred care, social robot, technology

Background

The growing prevalence of older patients with dementia in hospitals demands that hospital staff find innovative ways to meet the needs of this population. Hospitalization rates are 65% higher for seniors with dementia than for those without (Canadian Institute for Health Information, 2018). Innovative assistive technologies, such as social robots, have been found to be helpful in long-term care, but there is an absence of evidence on how robots can be used effectively in hospitals (Lane et al., 2016; Lynn et al., 2019). Although there is growing emphasis on patient engagement in research on hospital service improvement, the voices and perspectives of patients with dementia have not been adequately recognized or reported (Heinz, Margrett, Franke, & Wong, 2013; Wu et al., 2016).

Restrictive clinical environments and an over-emphasis on physical needs in the hospital setting can result in overlooking the social and emotional needs of older people with dementia (Scerri, Scerri, & Innes, 2018). Many families (more than 90%) reported that the hospital

environment is frightening for patients with dementia (Alzheimer Society, 2016). Research has also found that the intentions of patients with dementia in the hospital ward are often misinterpreted as disruptive behaviour (Jensen, Pedersen, Olsen, Wilson, & Hounsgaard, 2018).

The use of social robots (a psychosocial approach) may have the potential to provide a positive influence that makes the hospital environment more supportive for older people. Using robotics to support the older population's needs is a rising field of research in healthcare. A variety of robots are available to assist with the care of older people. PARO is one of the more used socially assistive robots, having been successfully utilized for dementia care in multiple countries since 2003. The development of care using social robots was based on research of therapeutic effects of human—animal interaction; the intention of using robotic animals (similar to animal-assisted therapy) is to provide psychological (e.g., improve mood), physiological (e.g., reduce stress and stabilize blood pressure) and social benefits (e.g., connecting people) through interactions (Shibata & Coughlin, 2014). One systematic review on animal-assisted interventions for older people with dementia found that they had positive effects by reducing agitation and improving quality of social interaction (Bernabei et al., 2013). Another systematic review by Yakimicki, Edwards, Richards, and Beck (2019) found nine studies that showed the implementation of animal-assisted therapy yielded statistically significant results in reduction of agitation and aggression.

The robotic seal PARO was specifically designed for people with dementia; PARO weighs 2.8 kg and is 45 cm long (Wada & Shibata, 2008). It behaves like a domestic pet and responds to touch, light, sound, motion and temperature; its artificial intelligence enables machine learning to support the social and emotional needs of those who interact with it (Shibata & Coughlin, 2014). Globally, studies have reported the effects of PARO on older people with dementia in a wide range of situations and challenges in care settings. In the United States, Petersen, Houston, Qin, Tague, and Studley (2017) conducted a randomized controlled trial (RCT) and found that PARO decreased stress and anxiety in older people with dementia, which resulted in reductions in pain levels and in the use of antipsychotic medications and sleeping pills at a long-term care facility. Compared to the control group, patients in the PARO group had a significantly increased effect on galvanic skin response and pulse oximetry – these autonomic responses indicate reduction in stress and anxiety (Petersen et al., 2017). In Norway, an observation study based on video recording showed that PARO had positive engagement benefits in group activities; increases in smiling/laughing and conversation were found among residents in the nursing homes (Jøranson et al., 2016). In Denmark, an RCT study compared the behavioural responses of nursing home residents to a person accompanied by a live dog, PARO, or a toy cat; the results indicated PARO and the dog triggered the most interaction, compared with the toy cat (Thodberg et al., 2016).

Although PARO has been studied in long-term care settings, the use of this robotic intervention has not been researched and reported in the hospital setting, where dementia care is highly challenging. Also, there is a lack of research on understanding the perceptions and experiences of using social robots among people with dementia in the hospital. Research is needed to understand how technology can help to support psychosocial needs of people with dementia. When people with dementia are hospitalized, the key challenges for them are unfamiliar surroundings and nurses not having adequate knowledge and resources to offer psychosocial interventions to optimize person-centred care (Handley, Bunn, and Goodman, 2019; Hung, Son, & Hung, 2018; Möhler & Meyer, 2014). Anxiety and boredom and lack of

meaningful activities are common problems for people with dementia staying in hospital wards (Handley et al., 2019). Central theories that involve person-centred care can be used to guide PARO research, explaining how technology may help support psychosocial needs of patients with dementia in hospitals (Hung et al., 2019). As indicated by Jøranson, Pedersen, Mork Rokstad, and Ihlebaek (2015), the social robot intervention could be seen as a tailored activity aiming to meaningfully engage the person with dementia, a person-centred care approach to meet unmet needs. Person-centered care involves using a holistic approach (including environment) to meet the person's five fundamental psychosocial needs: attachment, occupation, identity, comfort and inclusion (Kitwood, 1993).

The purpose of this study was to answer two research questions: (1) 'How do hospitalized patients with dementia respond to the social robot PARO?' and (2) 'How can the social robot be used most effectively to support the needs of patients with dementia in the hospital setting?' Specifically, this study focuses on reporting patients' experiences of using the social robot in a hospital ward (research question 1). The theoretical concepts of person-centred care were used to guide the research.

Methods

Setting and participants

The research was conducted at a geriatric mental health unit of a large urban hospital in Canada. The 19-bed unit provides assessment and treatment related to neurocognitive disorders and mental health illnesses for older adults. The majority of the patients on the unit have a diagnosis of dementia and other co-morbidities. The length of stay varies from two weeks to six months or longer.

Purposive sampling was used to identify patient participants to gather meaningful insights from a diverse group. We selected patients with different kinds of dementia, dissimilar functional disabilities, various ethnic backgrounds, both sexes, different ages, etc. Some participants were more fluent in linguistic expression; other participants had more communication and cognitive difficulties in social interactions. Screening tools such as the Mini-Mental State Examination were not used to exclude patient participants, as evidence from previous studies demonstrated that people with moderate-to-late dementia can contribute to research when adapted methods are used (Hung et al., 2017). Nurses who knew the patients on the unit helped to recruit patient participants with diverse characteristics to maximize variation. The characteristics of the patient participants are summarized in Table 1. Staff on the unit participated in one-to-one interviews and two focus group discussions. Staff experiences and the process of adoption will be written about in a future paper.

Ethical considerations

Ethical approval was obtained from both the University Research Ethics Board (H18-03483) and the local health authority (V18-03483). All staff participants signed written consent forms. For patient participants, we followed current evidence, treating consent as an ongoing process, seeking assent and respecting any dissent on the part of the participants (Black, Rabins, Sugarman, & Karlawish, 2010; Mann & Hung, 2018). The patient consent form was initially obtained from each patient or his/her family. A family member signed the participant information and consent form in cases when the patient participant was unable

Table 1. Descriptive characteristics of patient participants.

Characteristics	N (%)
Age (years)	
60–75	2 (20)
76–85	6 (60)
Older than 85	2 (20)
Gender	
Male	6 (60)
Female	4 (40)
Stages	
Early	2 (20)
Middle	5 (50)
Late	3 (30)
Ethnicity	
Caucasian	7 (70)
South Asians	2 (20)
Black	1 (10)

to do so. Verbal assent was sought before and during each interview session to remind patient participants about the purpose of the research and their right to withdraw at any time. In the consent form, the participants were given options to allow the researcher to use video or not in each interview. No participants objected to the use of video recording in the study. The participants were given the opportunity to review the edited video footage, and permission was obtained to use their direct quotes for publication and conference presentations. Pseudonyms were used to protect the participants' identity.

Instead of controlled experimental methods, we selected methods in video ethnography to conduct the research. Because some of the patients with dementia had difficulties with memory and linguistic expression, we adapted the methods of data collection to meet individual needs. For example, a familiar staff member helped to remind the person about the interview on the same day. The same staff member introduced the researchers to the patient participants. The researchers explained the research and used immediate environmental resources to support communication. The patient participants were encouraged to use their own ways to show and tell their experiences while the robot was placed in their hands (Hung, 2015).

Methodology

Theoretical grounding

This research was guided by theoretical principles of person-centred care (Kitwood, 1997). Person-centred care is characterized by an affirmation of personhood, which implies recognition, respect and trust (Fazio, Pace, Flinner, & Kallmyer, 2018). People with dementia may find themselves in a vulnerable position due to their progressive declines. This may lead to their gradual withdrawal from social contact, social exclusion and further deterioration of their condition. Kitwood (1997) asserted that the dementia experience is a dialectic between

cognitive impairment and multiple factors in the social environment and that a positive social environment can uphold and preserve personhood.

Drawing from Buber (1970), Kitwood (1997) argued that personhood is rooted in relationships and there are two kinds of attitudes on how we relate to other: 'I–thou' and 'I–it'. In the I–thou encounter, we relate to each other as authentic beings, a positive way of treating the other person as a respected human, a subject-to-subject relation. I–it is the opposite in that we relate to others as object, without acknowledging their concerns or feelings. Kitwood called the I-it way of relating as objectification, a malignant social psychology, which is damaging and hurtful to people with dementia, contributing to ill-being.

Kitwood also explained that the notion of personhood is linked to the five fundamental human psychosocial needs (comfort, attachment, occupation, identity and inclusion), with love being at the core. As Sabat (2018) explained, personhood is a sense of self that is developed and maintained through interactions with others. In other words, a sense of self can be supported through social interactions that promote personal worth (identity), agency (occupation), social confidence (inclusion), stress relief (comfort) and emotional connection (attachment). As the social robot PARO was designed to interact with users to support their psychosocial needs (Wada, Shibata, Musha, & Kimura, 2008), personcentred care offers a meaningful foundation on which to build the research. This study explores the complexity of human–robot and human–human interactions (mediated by the robot). We demonstrate and explain what happened when interaction and relationship-building took place in the hospital unit and when the robot PARO entered the clinical setting.

Data generation

Data generation involved (a) conversational interviews and observations with video recording among 10 patient participants while they were using the robot, (b) semi-structured individual interviews (30 minutes) with six staff members and (c) two focus groups (30 minutes each) with 10 nursing staff members. We focussed our efforts on conversations specifically about PARO because we wished to obtain insights into the patients' experience with the robot. Social conversation involves communicating emotions and maintaining identity more than facilitating facts about an experience (Dahlbäck, Forsblad, & Hydén, 2019). Staff who knew the patient participants well suggested the best time and location for the robot's use. The staff's decisions were based on situations when a patient participant might benefit from the social robot for support. For example, we interviewed a patient who was newly admitted and two patients who were leaving on discharge. Also, we observed a patient who was in emotional distress and another patient who needed PARO to cope with anxiety. We did not simply leave the robot with the patient. Each time, after introducing the robot, a staff member stayed to have a social conversation with the patient. Family coresearchers (CW & NH) conducted interviews and observations at various times of the day (mornings and afternoons) and in various locations (activity room, dining room, patient rooms and hospital waiting room).

In the social interaction, each patient was encouraged to tell stories that mattered to him or her. Patients were asked, 'What do you think about PARO? How does it make you feel? What does it mean to you?' Emergent questions were asked as relevant topics arose. The conversational interviews and interactions with the robot were captured on video. Each patient was interviewed and observed two to four times (about 20–30 minutes each time).

Data collection and analysis occurred in an iterative manner, so the early analysis informed the directions for later data collection. Also, clinicians who knew the patient participants provided additional contextual information to deepen the analysis. For example, one of the patient participants was very nervous about a treatment procedure. A patient co-researcher, JM, suggested sending PARO to accompany the patient for the procedure to ease anxiety and provide comfort. Staff in the focus group discussions provided more contextual information; they described and compared stories about when PARO was used and when it was not used. The multiple methods helped to generate a rich and detailed description of the patients' responses to the social robot in various clinical situations. The combination of interviews and observation in ethnography enabled us to meaningfully look at the interaction between patients and the robot in real-life clinical situations.

Data analysis

The video recordings were transcribed verbatim. The non-verbal actions (e.g., smiling, kissing and hugging or caressing the seal) were added to the transcript. All researchers, including patient and family co-researchers, watched the videos individually and with the team. The team analysis began with a review of Kitwood's (1997) concepts of personcentred care theory. A one-page handout with a visual diagram and description of the psychological needs was used to facilitate qualitative data analysis. The whole team read extracts and worked together to make sense of the data. The first author facilitated all team analysis sessions (n = 4; each lasted an hour). The team members brought up concepts that stood out to them for collective analysis. Individual assumptions and interpretations were compared and discussed to gain clarification.

Thematic analysis techniques were used to group codes and categories into themes (Braun & Clarke, 2006). Both inductive and deductive coding techniques were applied to illuminate data segments indicative of thematic patterns. Inductive codes were developed based on emergent data, and deductive codes were drawn from person-centred care theory and previous PARO research. Conceptual categories were refined by going back and forth between the data and the team discussion to develop empirically grounded themes that represented participants' experiences (see Table 2 for themes developed based on grouping categories and coding of examples of original quotations).

Findings

The analysis revealed three substantive themes characterizing the experiences of patient participants on how the social robot might support their needs in the hospital (a) 'it's like a buddy' – the robot helps people with dementia uphold a sense of self in the world, (b) 'it's a conversation piece' – the baby seal facilitates social connection and (c) 'it makes me happy' – PARO transforms and humanizes the clinical setting.

Theme 1: 'It's like a buddy': The robot helps people with dementia uphold or reclaim a sense of self in the world

People with dementia may have self-doubts and insecurities from time to time, as they are impacted by disease symptoms, hospitalization, stigma and changing life circumstances; a friend may be needed at those times. In the interviews, many patients called PARO 'a good

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Examples of original text/quotations	Codes	Categories	Themes
'It's like a buddy, I like him, and he likes me'. 'Do you like me? I don't like myself. You like me?	Recognition Having fun together	Inclusion Identity	'It's like a buddy' The robot helps
'Yes, you like me. Good, give me ten'.	Mutual respect		uphold or reclaim a sense of self in the world
'It's a conversation piece. It's kind of cute. PARO makes	Enabling emotion	Occupation	'It's a conversation piece' The baby earl facilitates
home for a long time, like a year, then you got home.	Facilitating social)racillelle	social connection
And it triggers memories. Remember the song: (singing) Like a bridge over troubled water'	connection • Validation		
'It makes me happy; I love it. I worried and I am sad about being here [hospital]. This [robot] should be used more	 Acknowledgement Warmth Holding 	Comfort	'It makes me happy' PARO transforms and humanizes
In the hospital to make patients happy.	Kelaxed atmosphere		the clinical setting

friend' or 'a buddy'. Our observations indicated that it took the patient participants very little time to accept PARO and bond with it. Here, we describe one example – Max. Max was one of the patient participants who complained about being abandoned by his family and friends. His cognitive decline and memory impairment aggravated the situation and evoked a greater need for social acceptance. He had been admitted to the hospital for behavioural and psychological symptoms of dementia (BPSD). He was a quiet person but showed frustration and angry behaviours towards himself and others. The following conversation extract shows how PARO helped Max to address the need for acceptance – a key psychological process for upholding a sense of self.

Staff Gail: (Showing PARO to Max) This is a social robot, PARO; it has sensors in his whiskers. If you talk to it, it responds to you.

Patient Max: (holding PARO and petting it with gentle strokes) Do you like me?

PARO: (moved its head toward Max and looked Max in the eye)

Max: (looked into PARO's eyes) I don't like myself.

Max: (kept petting the seal's body) You like me?

Researcher: I think it [PARO] likes you. It's looking right at you, Max. What do you think it's trying to say?

Max: I think it says, you are not a bad guy. You are okay.

PARO: (Moved its head and returned its gaze to Max with wide opened eyes. Then, it cooed with a nod.)

Max: (Max smiled). Oh man, you like me?

PARO: (leaned its body on Max, turned its head down and wagged its back flippers)

Max: What? I thought you liked me? (laughed)

PARO: (cooed, moved its head, and looked at Max; stayed still for a minute)

Max: Yes, you like me. (Cheered, raised his palm in the air.) Good, give me ten.

For Max, PARO's response mattered. The robot's spontaneous reaction made it very likeable. Max's question to the robot, 'Do you like me?' suggested a desire for emotional connection (attachment). The emotional bonding helped Max to meet the need of social acceptance (identity) and of gaining recognition as a valuable human being (inclusion). In the video, Max got very close to the robot and claimed, 'He kissed me'. When Max looked the robot in the eye, he interpreted the robot's reactions with social intentionality. In the conversation, turn-taking was evident: Each time Max asked PARO a question, he would wait for a response. Before he left the hospital, he asked PARO, 'Will you miss me? I am

leaving'. He summarized his experience with PARO, 'it's like a buddy, I like him, and he likes me'.

The robot's social capabilities were successful in relationship- and trust-building. Max not only sought affirmation of his personal worth but was also successful in gaining a sense of social approval. This example demonstrates that the person with dementia not only developed a relationship with the robot but also gained benefits from that relationship immediately. When Max was asked how the robot made him feel, he said: 'It makes me feel good and warm. He likes me. I like him. We are buddies'.

PARO was regarded as being worthy of respect. Patients seemed to expect a reciprocal relationship with the robot. A patient told us that PARO loved her and she loved it back. Another patient remarked, 'He is like a new friend. You treat it with respect. What you give, you will get back in return. I am absolutely getting something back from it'. Other patient participants commented that the robot was 'calming', 'friendly', 'cute' and 'good'. As the robot responded to human voices, motion and touch, patients held a certain attitude and expectations about how the robot should be treated. When a patient, Ben, was asked, 'What happens when you pet the seal?' Ben responded,

It feels like it's [PARO is] made of glass – fine glass that needs tender loving care or it will shatter. Because it's fragile. But there is a certain beauty about things that are fragile and that they need tender loving care. Just like people. If you treat them the way you want to be treated and enjoy their company, then it goes a long way. The happiness is with you and your friends.

Ben alluded not only to the value of friendship but also to how friendship involves mutual relations of goodwill and affection that consequently contribute to happiness. Ben used 'fine glass' to symbolize the baby seal and emphasized that it was frail and needed his care. People with dementia in the hospital setting were patients because doctors and nurses viewed them as the ones to be cared for. Rather than merely receiving care, having these opportunities to provide care and offer love to the robot seemed important and meaningful to Ben.

Theme 2: 'It's a conversation piece': The baby seal facilitates social connection

PARO provided a common conversation topic for social exchange. Patient participants remarked that PARO's presence offered positive stimulation. For instance, Ben said, 'It's a conversation piece. It's kind of cute'. The staff on the unit told us that Ben had difficulty expressing himself in care activities such as at mealtimes and toileting. However, in our interviews, while Ben was holding the robot, he had a lot to say about his emotions:

PARO makes me feels at home. It's like if you have been away from home for a long time, like a year, then you got home. And it triggers memories. Remember the song: (singing) 'Like a bridge over troubled water. I'm on your side, oh, when times get rough, I will comfort you . . .' Sometimes these things pop up to my head and, uh, most of them [are] good, some of them [are] not so good . . . Sometimes, it was almost as if he could hear me and came to life from his dormant state.

We noted that patients with advanced dementia seemed to be willing to talk to the robot. For those who had a word-finding problem, the robot seemed like a key that helped unlock and open up their ability to speak and express what they were thinking. The robot was designed to facilitate social connection and offer emotional support; it always gives a positive response

unconditionally. Without imposing any judgement, the robot did not correct the person but encouraged open expression. Ben explained: 'I know it's not going to talk back about something that is not kosher'. PARO gave the patients opportunities to express their emotions: 'I can tell him anything. It seems to come alive when I get excited about things. That's what makes it a good companion'. Ben's response suggested that he appreciated the robot was open to be with him in his subjective reality, offering a sense of validation and acknowledgement. Also, reminiscing provided patients another means to spark conversation and tell stories about their past. Spending time with PARO was a platform for sharing stories about one's place in the world. Knowing the robot was not a real and live being, Ben could feel free to talk to it. The robot does not judge him. At the end of an interview, Ben remarked, 'PARO is just like an old buddy. I know it's just a toy, of course'.

In some instances, the seal worked as a mediator and facilitated social connections. For example, when patients were admitted to the unit, PARO provided a non-threatening and welcoming way for staff to get to know the patients. One female patient who was depressed related PARO to a white cat that she used to have at home. She got very emotional in the interaction, held and cuddled PARO tight to her chest and kissed it many times. In another case, PARO was offered to a male patient who was nervous about his hospitalization. Interaction with PARO enabled the staff to get him to talk about his dogs and family life. Due to social stigma and misperception of dementia among hospital staff, patients with dementia in the hospital setting often experience a lack of opportunity for positive social engagement. Also, the loss of social role and purpose can threaten the older person's ability to sustain a sense of identity. When patients with dementia and staff were able to connect in a social exchange, the encounter honoured the patients' identities – it helped them feel validated and valued.

Although we introduced PARO to patients by telling them it was a robot, patient participants often treated PARO as if it was alive. Some gave PARO a name, Casper, because PARO may have reminded them of a popular childhood cartoon 'Casper, the Friendly Ghost'. Many patients referred PARO as 'he' or 'she' rather than 'it'. However, treating it as alive does not mean the patient participants did not know it was an object, not a real living being. One patient Victoria even joked, 'I am scratching his tummy. There are his batteries. He's not dead yet'. When Victoria was asked how PARO made her feel, she said, 'It makes me feel so friendly. I love you, oh my god, are you a friendly little seal? (singing cheerfully) I love you'. Then, she gave the robot a big kiss. She told the researchers, 'It kissed me. Hello, baby . . .'

Our video data show that the relationship between the patient and the robot opened up a special space for meaningful connection and emotional exchange. For example, seal meat is a traditional food for people in Northern Canada, and it brings memory and feelings of comfort. Victoria, who grew up in Newfoundland, told us that she loved PARO because 'I like the seal meat, the taste is good', to which everyone in the room laughed. She went on: 'My grandfather used to club the baby seals to make fur coats out of them'. Another patient, Asheesh, who spoke very limited words, told the staff that he would like to take PARO home and his family would love him. 'I like him too; I can sleep with him'. One patient, Paul, who also had more linguistic difficulty managed to say, 'This is cute, my pet. I like him'. He kissed PARO and handled it lovingly. One afternoon, a patient, Barry, was tearful after a family visit. PARO was used to comfort him. In our field work, it was notable that PARO was able to create intimate social connections with patients. As if there was a pet in the room, patients were more relaxed when they had PARO sitting on their laps. Consequently, they were able to express more verbal and non-verbal responses that enhanced communication.

Theme 3: 'It makes me happy': PARO transforms and humanizes the clinical setting

Life in the hospital unit can be a very stressful experience for people with dementia. The social attractiveness of PARO affects people emotionally and offers warmth and comfort. Our video footage showed that PARO actively made eye contact and leaned its head toward people like a domestic pet. When the robot was introduced, people changed the way they talked. We noticed lowered volume and a softer tone of voice, accompanied by animated facial expressions, smiles and laughter. One patient, Mei (a patient who was admitted for depression) appeared to be very excited about meeting PARO – she threw PARO in the air like a balloon and kept laughing. 'It makes me happy', she remarked. The video recording captured the joy Mei had with the robot, and their interaction made everyone laugh. In the middle of her interview, Mei insisted on taking PARO for a walk on the unit and showed PARO the aquarium in the sensory room. She told us that the robot should be used more in the hospital to make patients happy. Staff in the focus group told us that Mei was tearful and angry about her hospitalization; she shouted at other patients and staff. In contrast, the video data showed that Mei's interaction with the robot transformed the unit atmosphere into a relaxed and cheerful one.

Across the interview and video data, a sense of comfort, safety and stress relief were frequently noted and coded. For example, Victoria was nervous about diagnostic and therapeutic procedures. She screamed and yelled at staff when she had X-rays scans and electroconvulsive therapy (ECT). It was very difficult for Victoria when she had to sit in the ECT waiting room with strangers. The waiting room was crowded with inpatients and outpatients, hospital beds and medical equipment. The place was tense because it was filled with noise caused by equipment such as blood pressure machine and medical alarms. Also, there were security guards and police, as well as a large number of patients in stretchers and medical staff moving in and out. One morning, a staff member brought PARO and stayed with Victoria in the waiting room. As soon as PARO entered the room, the atmosphere of the waiting room changed. It was immediately filled with curiosity and warmth. People asked Victoria, 'What is that? Is it a toy?' Victoria explained: 'It's a robot, a baby seal . . . It likes catfish'. The social conversation seemed to reduce her worries and anxieties, as everyone in the room were engaged in learning and making comments about PARO. Our observation indicated that the application of social robot in the clinical environment led to not only more engaged behaviours but also stress relief.

Having a sense of safety and comfort was important to many patients who were experiencing cognitive and physical declines. When functional declines make communication more challenging, people with dementia experience vulnerability to social isolation and loneliness. Understandably, staff told us that patients displayed behaviours of anger and frustration when they felt ignored or not getting adequate needed attention. The robot can play a role in reducing social vulnerability by making itself available for unconditional emotional support. For example, in staff interview, the recreation staff told us that a patient, Bill, often refused care and would hit staff. He spent a lot of his time sitting by himself alone. When he met PARO, he smiled and petted it in his lap. He was able to talk to staff about PARO with a few broken words. In our video data, we found that Bill was able to benefit from physical touch and social gestures that the robot offered. In another video recording, we observed that Tom, another patient with anxiety and withdrawal, laughed while he was scratching PARO's chin and forehead. The robot offered comfort and emotional support while patients were

feeling vulnerable and stressed in the hospital. Overall, our results suggest that the robot is a promising tool to help humanize hospital care among patients with dementia.

Discussion

This study presents the opinions and experiences of patients with dementia in a geriatric hospital unit. The findings are based on patient interviews, observations and interpretations by the research team. To date, the perspectives of hospitalized patients with dementia about using PARO to support their care experiences have not been adequately examined. Our findings contribute to gaining understanding of the experiences of people with dementia using PARO in the hospital setting by providing a rich analysis of the direct perspectives of patients with dementia. We do not intend to claim that the results reported in the current study represent the experience of all patients with dementia. People with dementia are heterogeneous with a wide range of clinical profiles, different needs, abilities and disabilities. However, our interviews and observations provided useful insights related to person-centred care approaches, raising crucial questions for future research and practice. The perception of the participants can be characterized into three quotes in the final themes: 'it's a buddy', 'it's a conversation piece' and 'it makes me happy'. The three themes are not mutually exclusive but rather are interconnected. Based on person-centred care Kitwood (1997), our results show that patient participants perceived the robot PARO as helpful in supporting the psychosocial needs for inclusion, identity, attachment, occupation and comfort.

Inclusion and identity are two central psychosocial needs in the model of person-centred care; recognition, having fun together, acceptance and respect are essential 'positive person work' to uphold a person's personhood (Kitwood, 1997). Inclusion is about recognizing that the person is part of the group and is welcomed to the community despite whatever disabilities the person may have; identity relates to being accepted as who he or she is and being respected or held in esteem (Brooker, 2003; Hung & Chaudhury, 2011). The interview data indicated that the PARO activity with staff offered positive support and comfort to patients with dementia. Max, Ben, Mei, Tom and other patients used humour to interact with the robot and had enjoyable exchanges despite their worries and stresses about their hospitalization. The notion that people with dementia are able to have positive social interactions with PARO is not new and can be found in previous studies (Jøranson et al., 2016; Moyle, Bramble, Jones, Murfield, & Bowers, 2017; Robinson, MacDonald, Kerse, & Broadbent, 2013). However, how patients with dementia experience the robot in the hospital setting for social and emotional support is new. There is substantial literature that supports friendship as important for health and well-being, just as a good friend would cheer you up when you feel down, stay by your side when you feel the world rejects you. As de Medeiros, Saunders, Doyle, Mosby, and van Haitsma (2012) wrote, friendships in dementia care could clearly improve the quality of people's lives and serve as an important psychosocial means of improvement of affect, physical health and flourishing.

Intimate hugging and kissing were evident in the video data. Also, a staff member was always involved in the conversation, so the technology was not a substitute for staff. Some authors have raised the concern that PARO, which resembles a seal, may fool people into believing they are in a relationship with a real animal (Rabbitt, Kazdin, & Scassellati, 2015; Sharkey & Sharkey, 2012). Research by Wang, Sudhama, Begum, Huq, and Mihailidis (2017) on the views of older adults with Alzheimer's disease about social robots for home use found that older people felt they did not need robots and that robots would only be



Figure 1. Max and PARO.

useful for those who were in later stages of dementia. In our study, patients with various stages of dementia accepted the robot and viewed it as a special technological companion. Although they often treated it as a living being, they mentioned that they knew it was a toy or that it had batteries.

Occupation is an important psychosocial need, as suggested by Kitwood (1997), and relates to being involved in activities that are meaningful and having a sense of agency. Enabling emotional expression and facilitating social connection help to support the need for occupation. Consistent with the current literature (Bemelmans, Gelderblom, Jonker, & de Witte, 2015; Jøranson et al., 2016; Klein, Gaedt, & Cook, 2013), the robot served as a medium for facilitating social exchanges. Our results also demonstrated the presence of the robot enabled participants to talk and express themselves as well as facilitating social connection. We know from previous research that a positive social environment improves the linguistic ability of persons with dementia (Lane et al., 2016; Olsen, Pedersen, Bergland, Enders-Slegers, & Ihlebaek, 2019). Our findings pointed to PARO's ability to create a supportive social environment and bring out the psychological and social strengths of people with dementia. Our results show that the patient participants were not passive recipients of the robotic therapy but active agents who used their agency to create a positive social experience. Figure 1 shows a picture of Max interacting with PARO.

Attachment is a psychosocial need that relates to bonding, affection, trust and relationship (Brooker, 2003). Kitwood (1997) underlined that attachment needs to be supported by genuine acknowledgement and validation. In the study, the robot was talked with as if it were a person capable of understanding human emotion. Buber argued that people's relating to others in the 'I-thou' relationship is what makes us human. Kitwood asserted that person-

centred care is rooted in the 'I-thou' relationship, respecting others as whole beings, regardless of their disabilities. In the 'I-thou' positioning, the reality of the person with dementia is acknowledged and validated. Acknowledgement and validation are salient in supporting attachment needs when the person with dementia is feeling vulnerable or in stress. In contrast, Kitwood considered that in the 'I-it' relationship, the other is treated as an object, an action that dehumanizes or degrades someone. Kitwood defined 'objectification' as treating the person as dead matter or as an object, which undermines personhood. Kitwood has been criticized for keeping personhood in the 'I-thou' relationship, leaving the responsibility for sustaining personhood in the hands of the carer and neglecting the agency of the person with dementia (Higgs & Gilleard, 2016). Interestingly, although the patients were in an 'I-it' relationship with the robot (it), they projected their emotions onto the robot. When PARO opened its big eyes and turned to or leaned on the person, PARO invited a sense of relationship. PARO's interactive capacities made it effective in generating emotional attachment. The social robot was designed to interact with people, and it is a socially constructed object in human discourse. The meaning of the robot was socially and culturally created by those who interacted and talked with and about it. Future research should further examine human-robot interaction and how it may impact care practice in dementia.

Comfort, a key psychosocial need is about the provision of tenderness, closeness and soothing; it promotes security and decreases anxiety (Kitwood, 1997). In the study, comfort was provided through the sensory touch and gesture offered by the robot. Similar to the results in studies at long-term care homes (Marti, Bacigalupo, Giusti, Mennecozzi, & Shibata, 2006; Moyle, Bramble, Jones, & Murfield, 2018), the robot in the hospital setting in our study helped to create a relaxed atmosphere for people to experience warmth, affection and care. The example of Victoria in ECT treatment is a good example of showing how the robot was effectively used to provide 'holding'. Kitwood (1997) explained that 'holding' means offering a sense safety, security and comfort when the person with dementia requires attention and support.

In long-term care, PARO was seen as a means to support relational care as residents could have PARO over a long period of time (Moyle et al., 2018). However, the stay of patients in a hospital setting is short so the introduction of PARO will heavily rely on staff. If hospital staff value medical task over psychosocial interventions, PARO would be stored on the shelf, not used. Also, hospitals have strict policy in infection control so obtaining leadership approval and providing staff training on cleaning protocol are essential parts of the implementation process. As pointed out by Lane at al. (2016), getting staff to accept and routinely use PARO can be challenging. There are barriers such as a lack of knowledge and awareness of the patients' needs, staffing issues, training issues, organizational issues, funding and technophobia. Knowledge translation research is needed to understand what enables and hinders adoption by staff in interdisciplinary teams in the hospital setting. It is important to point out that PARO may offer an attractive and healthful activity for patients who are interested in social robots, but it cannot fully address complex challenges that people with dementia face in the hospital setting.

Strengths and limitations

Because the primary objective of this research was to understand and improve patient experience, we adapted methods to bring out the direct voices of patients with different

dementias. The research team was made up of interdisciplinary clinicians (a nurse, physicians and an occupational therapist) and patient and family partners. Our diverse backgrounds, expertise and perspectives enhanced the robustness and credibility of the research. The qualitative methods allowed us to provide a detailed description of the context, participants and methods for generating the data. Direct quotes from the narratives were used to help readers deepen their understanding of our observations. The naturalistic field work allowed us to gain a realistic understanding of how social interactions spontaneously emerge with the robot and evolve in the hospital setting. Video data strengthened scientific rigour by providing detailed data about the very subtle and complex proceedings in time and space for in-depth and repeated analysis.

Due to the limitation of the individual length of stay in the hospital, the patient participants' responses were gathered in two to four observation sessions. None of the participants had met PARO before. We do not know to what extent the novelty effect contributed to their positive response. We also do not know if the effect would be maintained, increased or decreased over a longer timeframe. Most of our patients were in the middle to later stages of the disease process. More than half of the participants were Caucasian. Future research should explore the role the robot plays for people with different racial and ethnic backgrounds and with various levels of cognitive and physical abilities. The presence of researchers in the setting may also have had an effect on the social atmosphere. The patient participants may have given positive responses because they thought that was what the researchers wanted to hear. Lastly, it is important to note that the relational skills of staff members may have been a critical factor in facilitating the patients' responses.

Conclusion

Our findings suggest that patients with dementia in the hospital unit perceived the social robot PARO as helpful for supporting their psychosocial needs. This study increases our understanding of the experience of older people with dementia using PARO in hospital. The robot was a viable psychosocial approach and well accepted by patient participants. This affirms previous research in long-term care that PARO can generate positive emotional and social responses in patients with dementia. As the growing evidence indicates that social robots offer positive impacts, more research should investigate how they may be used effectively to humanize hospital care for older patients with cognitive impairment, who are highly vulnerable in the hospital setting.

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Patient consent statement

The patient consent form was initially obtained from each patient or his/her family. A family member signed the participant information and consent form in cases when the patient participant was unable to do so. Verbal assent was sought before and during each interview session to remind patient participants about the purpose of the research and their right to withdraw at any time.

References

- Alzheimer Society UK (2016). Fix Dementia Care: Hospitals. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix dementia care hospitals.pdf
- Bemelmans, R., Gelderblom, G. J., Jonker, P., & de Witte, L. (2015). Effectiveness of robot Paro in intramural psychogeriatric care: A multicenter quasi-experimental study. *Journal of the American Medical Directors Association*, 16, 946–950. DOI: 10.1016/j.jamda.2015.05.007.
- Bernabei, V., De Ronchi, D., La Ferla, T., Moretti, F., Tonelli, L., Ferrari, B., . . . Atti, A. R. (2013). Animal-assisted interventions for elderly patients affected by dementia or psychiatric disorders: A review. *Journal of Psychiatric Research*, 47(6), 762–773. DOI: 10.1016/j. jpsychires.2012.12.014.
- Black, B., Rabins, P., Sugarman, J., & Karlawish, J. (2010). Seeking assent and respecting dissent in dementia research. *Nursing Older People*, 22(3), 14. DOI: 10.1097/JGP.0b013e3182423bcb.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. DOI: 10.1191/1478088706qp063oa.
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13, 215–222. DOI: 10.1017/S095925980400108X.
- Buber, M. (1970). I and Thou. New York: Touchstone.
- Canadian Institute for Health Information (2018). Dementia in hospitals. Retrieved from: https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-hospitals#admission
- Dahlbäck, N., Forsblad, M., & Hydén, L. (2019). Reflections and comments on research on memory and conversation from an ethnographic perspective. *Topics in Cognitive Science*, 11(4), 817–820. DOI: 10.1111/tops.12399.
- de Medeiros, K., Saunders, P. A., Doyle, P. J., Mosby, A., & van Haitsma, K. (2012). Friendships among people with dementia in long-term care. *Dementia*, 11(3), 363–381. DOI: 10.1177/1471301211421186.
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *Gerontologist*, 58, S10–S19. DOI: 10.1093/geront/gnx122.
- Handley, M., Bunn, F., & Goodman, C. (2019). Supporting general hospital staff to provide dementia sensitive care: A realist evaluation. *International Journal of Nursing Studies*, 96, 61–71. DOI: 10.1016/j.ijnurstu.2018.10.004.
- Heinz, M., Margrett, J., Franke, W., & Wong, J. (2013). Perceptions of technology among older adults. *Journal of Gerontological Nursing*, 39(1), 43–51. DOI: 10.3928/02793695-20110329-02.
- Higgs, P., & Gilleard, C. (2016). Interrogating personhood and dementia. *Aging and Mental Health*, 20(8), 773–780. DOI: 10.1080/13607863.2015.1118012.
- Hung, L. (2015). Exploring the co-construction of meaning and power relations in walk-along interviews with individuals with dementia. Gerontologist, 55(S2), 23. DOI: 10.1093/geront/ gnv161.02.
- Hung, L., & Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. *Journal of Aging Studies*, 25(1), 1–12.

Hung, L., Liu, C., Woldum, E., Au-Yeung, A., Berndt, A., Wallsworth, C., . . . Chaudhury, H. (2019). The benefits of and barriers to using a social robot PARO in care settings: A scoping review. *BMC Geriatrics*, 19(1), 232. DOI: 10.1186/s12877-019-1244-6.

- Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J., & Bohl, D. (2017). "Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. International Journal of Older People Nursing, 12(3), e12153. DOI: 10.1111/opn.12153.
- Hung, L., Son, C., & Hung, R. (2018). The experience of hospital staff in applying the Gentle Persuasive Approaches to dementia care. *Journal of Psychiatric and Mental Health Nursing*, 26, 19–28. DOI: 10.1111/jpm.12504.
- Jensen, A. M., Pedersen, B. D., Olsen, R. B., Wilson, R. L., & Hounsgaard, L. (2018). "If only they could understand me!" Acute hospital care experiences of patients with Alzheimer's disease. *Dementia*. Advance online publication. DOI: 10.1177/1471301218820483.
- Jøranson, N., Pedersen, I., Mork Rokstad, A. M., & Ihlebaek, C. (2015). Effects on symptoms of agitation and depression in persons with dementia participating in robot-assisted activity: A clusterrandomized controlled trial. *Journal of the American Medical Directors Association*, 16, 867–873. DOI: 10.1016/j.jamda.2015.05.002.
- Jøranson, N., Pedersen, I., Rokstad, A. M. M., Aamodt, G., Olsen, C., Ihlebæk, C., . . . Ihlebæk, C. (2016). Group activity with Paro in nursing homes: Systematic investigation of behaviors in participants. *International Psychogeriatrics*, 28(8), 1345–1354. DOI: 10.1017/S1041610216000120.
- Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry*, 8, 541–545. DOI: 10.1002/gps.930080702.
- Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University.
- Klein, B., Gaedt, L., & Cook, G. (2013). Emotional robots. *GeroPsych*, 26(2), 89–99. DOI: 10.1024/1662-9647/a000085.
- Lane, G. W., Noronha, D., Rivera, A., Craig, K., Yee, C., Mills, B., & Villanueva, E. (2016). Effectiveness of a social robot, "Paro," in a VA long-term care setting. *Psychological Services*, 13, 292. DOI: 10.1037/ser0000080.
- Lynn, D. J., Rondón-Sulbarán, J., Quinn, E., Ryan, A., McCormack, B., & Martin, S. (2019).
 A systematic review of electronic assistive technology within supporting living environments for people with dementia. *Dementia*, 18, 2371–2435. DOI: 10.1177/1471301217733649.
- Mann, J., & Hung, L. (2018). Co-research with people living with dementia for change. *Action Research*. Advance online publication. DOI: 10.1177/1476750318787005.
- Marti, P., Bacigalupo, M., Giusti, L., Mennecozzi, C., & Shibata, T. (2006, October). Socially assistive robotics in the treatment of behavioural and psychological symptoms of dementia. In *Proceedings of the First IEEE/RAS-EMBS International Conference on Biomedical Robotics and Biomechatronics*, 2006, BioRob 2006 (pp. 483–488). Piscataway, NJ: IEEE. DOI: 10.1109/BIOROB.2006.1639135.
- Möhler, R., & Meyer, G. (2014). Attitudes of nurses towards the use of physical restraints in geriatric care: A systematic review of qualitative and quantitative studies. *International Journal of Nursing Studies*, 51(2), 274–288. DOI: 10.1016/j.ijnurstu.2013.10.004.
- Moyle, W., Bramble, M., Jones, C., & Murfield, J. (2018). Care staff perceptions of a social robot called Paro and a look-alike plush toy: A descriptive qualitative approach. *Aging and Mental Health*, 22, 330–335. DOI: 10.1080/13607863.2016.1262820.
- Moyle, W., Bramble, M., Jones, C. J., Murfield, J. E., & Bowers, B. J. (2017). "She had a smile on her face as wide as the great Australian bite": A qualitative examination of family perceptions of a therapeutic robot and a plush toy. *Gerontologist*, 59(1), 177–185. DOI: 10.1093/geront/gnx180.
- Olsen, C., Pedersen, I., Bergland, A., Enders-Slegers, M.-J., & Ihlebaek, C. (2019). Engagement in elderly persons with dementia attending animal-assisted group activity. *Dementia*, 18, 245–261. DOI: 10.1177/1471301216667320.

Petersen, S., Houston, S., Qin, H., Tague, C., & Studley, J. (2017). The utilization of robotic pets in dementia care. *Journal of Alzheimer's Disease*, 55(2), 569–574. DOI: 10.3233/JAD-160703.

- Rabbitt, S. M., Kazdin, A. E., & Scassellati, B. (2015). Integrating socially assistive robotics into mental healthcare interventions: Applications and recommendations for expanded use. *Clinical Psychology Review Integrating*, 35, 35–46. DOI: 10.1016/j.cpr.2014.07.001.
- Robinson, H., MacDonald, B., Kerse, N., & Broadbent, E. (2013). The psychosocial effects of a companion robot: A randomized controlled trial. *Journal of the American Medical Directors Association*, 14(9), 661–667. DOI: 10.1016/j.jamda.2013.02.007.
- Sabat, S. R. (2018). Alzheimer's Disease and Dementia: What Everyone Needs to Know. London: Oxford University Press.
- Scerri, A., Scerri, C., & Innes, A. (2018). The perceived and observed needs of patients with dementia admitted to acute medical wards. *Dementia*. Advance online publication. DOI: 10.1177/ 1471301218814383.
- Sharkey, A., & Sharkey, N. (2012). Granny and the robots: Ethical issues in robot care for the elderly. *Ethics and Information Technology*, 14(1), 27–40. DOI: 10.1007/s10676-010-9234-6.
- Shibata, T., & Coughlin, J. F. (2014). Trends of robot therapy with neurological therapeutic seal robot, PARO. *Journal of Robotics and Mechatronics*, 26(4), 418–425.
- Thodberg, K., Sørensen, L. U., Videbech, P. B., Poulsen, P. H., Houbak, B., Damgaard, V., . . . Christensen, J. W. (2016). Behavioral responses of nursing home residents to visits from a person with a dog, a robot seal or atoy cat. *Anthrozoos*, 29(1), 107–121. DOI: 10.1080/08927936.2015.1089011.
- Wada, K., & Shibata, T. (2008). Social and physiological influences of robot therapy in a care house. *Interaction Studies*, 9(2), 258–276. DOI: 10.1075/is.9.2.06wad.
- Wada, K., Shibata, T., Musha, T., & Kimura, S. (2008). Robot therapy for elders affected by dementia. *IEEE Engineering in Medicine and Biology Magazine*, 27(4), 53–60. DOI: 10.1109/MEMB.2008.919496.
- Wang, R. H., Sudhama, A., Begum, M., Huq, R., & Mihailidis, A. (2017). Robots to assist daily activities: Views of older adults with Alzheimer's disease and their caregivers. *International Psychogeriatrics*, 29(1), 67–79. DOI: 10.1017/S1041610216001435.
- Wu, Y.-H., Cristancho-Lacroix, V., Fassert, C., Faucounau, V., de Rotrou, J., & Rigaud, A.-S. (2016). The attitudes and perceptions of older adults with mild cognitive impairment toward an assistive robot. *Journal of Applied Gerontology*, 35(1), 3–17. DOI: 10.1177/0733464813515092.
- Yakimicki, M. L., Edwards, N. E., Richards, E., & Beck, A. M. (2019). Animal-assisted intervention and dementia: A systematic review. Clinical Nursing Research, 28, 9–29. DOI: 10.1177/ 1054773818756987.
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