Nursing home residents with cognitive impairment can participate in advance care planning: a qualitative study
Abstract

Aims

To describe advance care planning in nursing homes when residents with cognitive impairment and/or their next of kin participated and identify associated challenges.

Design

A qualitative study of nine advance care planning conversations in four Norwegian nursing home wards. During the implementation of advance care planning, we purposively sampled residents with cognitive impairment, their next of kin and health care personnel. The implementation followed a ‘whole-ward’ approach aimed at involving the whole ward in fostering an inclusive, holistic advance care planning discussion. Involving as many residents as possible, preferably together with their next of kin, were central.

Methods

From observed and audio-recorded advance care planning conversations that took place from November 2015 - June 2016, we conducted a thematic analysis of the transcripts and field notes. Reporting adhered to the COREQ guidelines.

Results

Residents actively relayed their preferences regarding health care and end-of-life issues, despite the cognitive impairment. Next of kin provided constructive support and conversations were largely resident-focused. However, involving residents was also challenging, findings included: residents’ preferences were often vague, relevant medical information from health care personnel lacked and the next of kin were sometimes unaware of the resident’s previously held preferences. Moreover, residents tended to focus more on the past and present than the future end-of-life care.
Conclusions

Residents with cognitive impairment can participate actively and meaningfully in advance care planning, if the health care personnel actively listens. However, several challenges can arise. Supported decision-making can improve communication and resident involvement, reinforcing a relational understanding of autonomy.

Impact

Persons with cognitive impairment should be invited to participate in advance care planning. Their participation may make its benefits and more person-centered care attainable to persons that are often not involved. Successful involvement of persons with cognitive impairment in advance care planning may rely on robust implementation.

Keywords

advance care planning, cognitive impairment, long-term care, nursing home, qualitative research, relational autonomy, whole-system approach, nursing
INTRODUCTION

Advance care planning (ACP) is an evidence-based approach to secure person-centered health care and is particularly important for severely ill, frail older patients (Mignani, Ingravallo, Mariani, & Chattat, 2017; Sharp, Moran, Kuhn, & Barclay, 2013). ACP represents a communication process that helps a person express goals and preferences for primarily future medical treatment and care and discuss these with their next of kin and health care personnel (Rietjens et al., 2017; Sudore et al., 2017). It is a way of involving patients in decision-making processes and involves extensive communication aimed at identifying a person’s end-of-life values and preferences. ACP is a crucial component of quality end-of-life care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Fosse, Schaufel, Ruths, & Malterud, 2014). While the nursing home environment is the focus of this study, ACP is relevant to nursing and health care professionals in other contexts.

BACKGROUND

ACP is internationally endorsed as a means of involving patients in their medical decision-making processes, which is a current and pressing goal within the health care community. Involving patients in end-of-life decision-making is based on theories of respect for patient autonomy (Beauchamp & Childress, 2019), person-centered care (O’Connor & Purves, 2009) and discourse ethics (Bohman & Rehg, 2017).

Unfortunately, many nursing home residents who want to participate in ACP are not included (Gjerberg, Lillemoen, Forde, & Pedersen, 2015; Mignani et al., 2017). Residents with cognitive impairment, i.e. trouble remembering, concentrating, or making decisions, may require support to participate. Their right to supported decision-making is protected by The United Nations Convention on the Rights of Persons with Disabilities (Devi, Bickenbach, & Stucki, 2011). Next of kin may have an invaluable role in supported decision-making, but their role in ACP is not clearly defined. Recently, there has been increased interest in
including patients with cognitive impairment in the ACP process (Rietjens et al., 2017) and recommendations for health care personnel have been published for ACP in dementia (Piers et al., 2018). Still, empirical research and standardized guidelines on ACP for patients with dementia remains limited (Bryant et al., 2019; Dixon, Karagiannidou, & Knapp, 2018; Wendrich-van Dael et al., 2020). Very few studies address how ACP is actually implemented in nursing homes (Flo et al., 2016).

Nursing homes are a part of Norway’s largely publicly funded health care system. Most residents have dementia (Roen et al., 2017) and are otherwise characterized by advanced age, comorbidity and frailty (Sandvik, Selbæk, Bergh, Aarsland, & Husebo, 2016). Four out of five nursing home residents have extensive care needs and are at least 80 years old (Helsedirektoratet, 2017). In 2018, the average physician spent 0.56 hours per week with an average resident (StatBank Norway). Since around half of all deaths in Norway occur in nursing homes (the Norwegian Institute of Public Health), ACP is of particularly relevance and of utmost importance to this environment.

This qualitative study of ACP observations is a sub-study of a larger research project on end-of-life communication in Norwegian nursing homes (Trygve Johannes Lereim Sævareid et al., 2018). We gave implementation support to nursing homes in the intervention arm of the project, following a train-the-trainer structure (Trygve Johannes Lereim Sævareid et al., 2018). The implementation strategies reflected a ‘whole-ward’ or ‘whole-system’ approach to ACP (Gilissen et al., 2017). Central to this type of approach is involving the entire ward in ACP. This entails including as many staff members as possible in the process and potentially making ACP a part of the ward care culture. Additionally, as many patients as possible should be involved.

Our whole-ward approach to ACP included: 1) Training and supervising nurses, nurses’ aides and physicians in the use of an ACP guide (Lisbeth Thoresen et al., 2017). The ACP guide
gave an introduction to what ACP is and when to implement it. Further, it gave recommendations on how to carry out ACP and how to involve residents or next of kin. The guide included questions like ‘how do you find living here?’, ‘do you have any worries for the future?’ and questions regarding preferences on future hospitalization, life-sustaining treatment and goals for end-of-life care. Health care personnel were recommended to use the ACP guide actively during conversations. However, our implementation support emphasized conversations should be adapted to the individual resident. If the resident seemed uncomfortable about certain questions those issues should be dropped or changed. 2) The management in the ward and nursing home supported the idea and implementation of ACP. 3) We encouraged residents with cognitive impairment to participate as much as possible. Implementation support included training in the assessment of decision-making capacity. 4) We encouraged next of kin to participate as much as the resident allowed – primarily together with the resident or as a subsidiary alone if the resident was not able to participate. 5) We acknowledged ACP to be a process consisting of more than one conversation and both formal and informal conversations. Thus, we encouraged being attentive and responding to residents’ initiatives in everyday situations concerning their existential worries or needs; these situations were referred to as ‘windows of opportunity’ (Seymour, Almack, & Kennedy, 2010). 6) We emphasized that participation in ACP is strictly voluntary (Mignani et al., 2017). 7) In contrast to several other ACP programs (Brazil et al., 2018; Detering, Hancock, Reade, & Silvester, 2010; In der Schmitten et al., 2014; Respecting Choices), our approach did not include external facilitators or an advance directive.

THE STUDY

Aims

The aims of this study were to describe advance care planning in nursing homes when residents with cognitive impairment and/or their next of kin participated and identify
associated challenges. Our research questions were: 1. What characterizes ACP conversations in long-term nursing home wards after 6-12 months of implementation support using a whole-ward approach? 2. What main challenges arise in these conversations?

**Design**

This qualitative study reports on observations made from audio-recorded ACP conversations in four nursing home wards. Reporting aligned with the COREQ guidelines. The ACP conversations took place between November 2015 and June 2016.

**Sample/Participants**

Participants were residents, next of kin or health care personnel in nursing homes in the intervention arm of the project. Conversations took place during the intervention period. The researcher had no established relationships with the residents or their next of kin. Some of the participating health care personnel had met the researcher as a part of training and supervision prior to collecting data.

Patients and next of kin agreed to being observed as part of being invited to the conversation by ward staff. We did not provide health care personnel with explicit criteria for deciding which residents were eligible to participate in ACP. However, we instructed them to use their knowledge of the resident as guidance. If the staff assessed the resident as unable to participate in any meaningful ACP conversation, the next of kin were invited to participate in the ACP conversation as a representative of the resident.

Staff at the nursing homes notified the researchers about conversations available for observation. No criteria other than consent from participants were given for selection of conversations to be observed and analyzed.
Ethical considerations

The Data Protection Official for Research at the Norwegian Centre for Research Data approved this study (reference number 41114). All participants, residents, next of kin and health care personnel signed an informed consent form before the ACP process was initiated. We informally assessed decision-making capacity based on criteria to determine competence to consent (Grisso & Appelbaum, 1998). We found all residents were competent to sign the informed consent form, even though some had reduced capacity for making future treatment decisions on their own. These residents were still able to consent to participate in this study because that decision required less complex information, e.g. time, risks, benefits and alternatives, than decisions about future treatment. This study conforms to the standards of the Declaration of Helsinki.

Data gathering and researcher roles

The first author (registered nurse and Master of Social Science), a PhD candidate with an interest in end-of-life decision-making at the time of the study, did the observations and audio recordings. Residents and next of kin were not provided with any additional information about the researcher. He placed an audio recorder such that it was visible to all participants and always sat in the eye line of the residents and their next of kin. His role during conversations were to observe and write notes of interest to the research questions of the study. Although he did not take part in the conversation by commenting or asking questions, his presence had an inevitable effect on the participants. Such “observer effects” should be considered as important data open to interpretation that can give important insights (Monahan & Fisher, 2010). An observation guide provided information to the researcher regarding the focus of the observations: who participated and where, the use of the guide, how participants were involved in the conversation, how participants interacted and any particular reactions
during the conversations. The first author wrote field notes during conversations, which were further developed following the conversation.

Observation provides a greater understanding of people’s actions, interactions, manners and values in their natural setting (McNaughton Nicholls, Mills, & Kotecha, 2014). However, positioning in social relations effects what is seen and how it is seen (May & Perry, 2014). The notes included the researcher’s reflections, elaborations and reactions after the conversations, for example, unexpected occurrences and deviations from the recommendations included in the guide and training.

**Analytical process**

Audio recordings were transcribed verbatim, either by the first author or research assistants. Transcripts were not returned to the participants for comments. To analyze themes and patterns in the transcribed audio recordings and field notes, we conducted a six-step thematic analysis (Braun & Clarke, 2006, 2013). In general, a theme encapsulates an important element of the data set in relation to the research question (Braun & Clarke, 2006). In thematic analysis specifically, a theme refers to a patterned response present across the data set. Themes can provide important answers to the research question (Braun & Clarke, 2013). All of the authors read through all of the transcribed conversations and field notes. The first author used NVivo 11 in coding and the analysis process, according to Braun & Clarke (2006, 2013). All authors participated in the development of the themes. The most relevant themes were further developed, refined and named through draft revisions of the article – to improve fit to the research question.

Themes were mostly developed through the analysis of transcribed audio recordings. Field notes provided rich details on the participating individuals and general aspects of the conversations. Field notes, thereby, provided invaluable insight into the conversations.
Both co-authors were Ph.D.-level researchers at the University of Oslo experienced in qualitative research at the time of data analysis. Lisbeth Thoresen is a female nurse who has worked extensively with qualitative methods and with death and dying-related topics. Reidar Pedersen is a male medical doctor and philosopher with expertise that include clinical ethics and end-of-life decision-making.

**Rigour**

The research questions drove the analysis and were formed both by empirical research and theory (in particular theories on patient autonomy, person-centered care and discourse ethics). The researchers strived to be open to the data during the analysis, while also acknowledging that approaching data analysis with a ‘blank mind’ is not possible (Heimbrock & Meyer, 2010). Thus, the analysis was both data- and theory-driven. Furthermore, we ensured rigor through describing advance care planning in rich and authentic detail (Lewis, Ritchie, Ormston, & Morrell, 2014).

**FINDINGS**

Two main characteristics of the ACP conversations were: 1) *residents with cognitive impairment can participate in ACP*; and 2) *next of kin play an important role in supporting residents with cognitive impairment*. The five main *challenges* related to these conversations were: 1) resident’s preferences were often *vague*; 2) *planning for end-of-life care was often not on the residents’ agenda*; 3) the impact of *cognitive impairment*; 4) health care personnel failed to provide *relevant medical information*; and 5) the *uncertainty* among next of kin regarding the resident’s previously reported preferences.
General observations

Here we provide context to and descriptions of the observed conversations. Detailed information can potentially adjust the reader’s preconceptions of what is observed and help others understand and evaluate the findings. More, it helps answer our research question 1. These conversations produced 167 pages of transcribed material and 13 pages of field notes. The conversations lasted from 19 – 55 minutes and were longer, on average, when the ACP guide was included in the conversation, when the resident participated and when four or more people participated in the conversation.

In total, we observed nine ACP conversations (from nine different residents) in four nursing home facilities. Communication difficulties caused primarily by advanced dementia prevented resident participation in four of the nine conversations. See Table 1 for more details on conversation participants. Non-participants were not present during the ACP conversations, except one student observing one conversation.

All residents present in ACP conversations had cognitive impairment and at least one had a dementia diagnosis. Cognitive impairment, for the purpose of this study, encompassed memory deficiency, reduced ability of focus or incoherent speech, and was likely induced by either the aging processes or dementia. One resident seemed to have little understanding of what the conversation was about, he had forgotten information provided by the nurse. All residents expressed whole sentences, but two talked more or less incoherently and had trouble focusing on the questions. The reason for not knowing exactly how many had dementia is because we did not gather data on diagnoses of participants. All had extensive care needs but were in a stable condition without any acute medical condition. Residents, whether taking part in the conversation or not, had at the time of the conversation been at the nursing home from almost a half a year to several years.
Nurses dominated conversations concerning psychosocial topics like socializing with others in the nursing homes or activities of daily living topics like nutrition. Physicians typically led the conversations regarding end-of-life care. Treatment intensity seemed to be discussed less when no physician was present.

Humor, laughter, smiles and an informal tone characterized most of the conversations residents took part in. In contrast, conversations with next of kin had a more formal tone with participants showing less emotion, even though a couple of the next of kin appeared moved when the end of life was brought up. In addition, we perceived conversations without residents as more formal because there were fewer interruptions and seemed less “chatty.” Our overall impression was that a trusting relationship had been established between resident/next of kin and carers.

The sensitivity of discussing the end of life can be demanding for those involved in ACP. A couple of nurses seemed uncomfortable discussing this topic in addition to life-sustaining treatment and hospitalization options. These nurses tended to use many words when asking a question, left sentences unfinished, focused heavily on the ACP guide and other materials and shifted their physical position while posing questions. We interpreted these signs of unrest as indications of being uncomfortable with the situation, but we have not checked for accuracy.

In line with recommendations from our implementation support, these ACP conversations typically started with health care personnel asking the residents or next of kin about the resident’s stay at the nursing home. From this, participants often discussed their admittance and settling in at the nursing home, past illnesses and relationships. Conversations then often developed to be about current relationships and needs, as well as questions on future health care.

The degree to which health care personnel had the ACP guide present and used it during conversations varied. When the ACP guide was actively used (health care personnel were
either reading the guide or reading from the guide aloud), our observations and audio recordings indicated stronger compliance with its recommendations. Conversely, when the guide was infrequently used, the conversations tended to be less in line with its recommendations. For example, resident’s information requests, participation in decision-making processes and hopes and worries for the future were less discussed in those conversations.

The observed ACP conversations tended to focus more on past and present experiences than future ones. When asked, four residents talked about dying and death in general, but often not their own thoughts about death, but rather their experiences with the death of others ... I know I will die, I know that, but I hope for the same death as my family had (Mille). Identifying residents’ preferences on end-of-life care and discussing end-of-life treatment were a part of eight of the nine conversations.

When the resident was not present, his or her’ situation and wishes, as far as these were known, remained the main focus of the conversations. The discussions were therefore primarily concerned with the interests of the resident, not the interests of their next of kin or health care personnel – what we attempt to find out, is what (the resident) may have responded, if she could respond (nurse).

Two conversations at one nursing home, however, suggested that some health care personnel were more preoccupied with informing the next of kin what treatment would be given in the case of deterioration, rather than exploring the resident’s previously reported preferences. For example, the next of kin was asked whether the resident had previously expressed any preferences in the event of acute, severe illness and answered: … she did before she became [too ill] (daughter). An outline of how the resident would be treated followed, instead of following up on the resident’s previously expressed preferences: – Before? Yes. What happens is, we try to treat or stabilize her at the nursing home (physician).
Residents with cognitive impairment can participate in ACP

In line with our implementation support, health care personnel and next of kin actively allowed room for residents to participate during the ACP conversations, despite the residents having varying degrees of cognitive impairment. Nevertheless, the health care personnel accepted this and let the resident talk. Residents, when involved, did most of the talking in these conversations.

Another way of involving and paying attention to the residents was related to the observation that health care personnel always sat close to residents. Several of them turned their chairs to face the resident. Their attention was directed at the resident, even when next of kin was present. Health care personnel did not overlook the next of kin, but they played second fiddle to the resident. While the next of kin sat close to residents, health care personnel were always closer.

Furthermore, health care personnel posed their questions directly to the resident, instead of to the next of kin, which contributed to involving the resident. Therefore, the residents became verbally active partners in the conversations. The residents seemingly knew the health care personnel well and talked with an apparent calm about personal issues like illness, loss of function and dependency. Moreover, the residents did not avoid eye contact and smiled and laughed frequently.

Importance of next of kin support

Next of kin played the role of supporting the resident when they were included in the conversation. They helped the resident remain focused on the topic of the conversation – *what the nurse asks is also about the day when we get so sick we get near the end of life, ..., do you want to have others than [name of the daughter] and myself present* (son in law). Next of kin could also comfort the resident during the conversation, as illustrated by Nora who claimed …
I forget sometimes, but her next of kin replied that’s not important (daughter). Next of kin also provided general information to increase health care personnel’s familiarity with the resident’s condition.

**Challenges related to ACP conversations**

Our observations indicated that nursing home residents with cognitive impairment can also participate meaningfully in ACP but challenges do arise.

**Vagueness**

Discussions that were too general contributed to a lack of clarity concerning residents’ preferences, although some insight was obtained. For example, a nurse asked Nora about her thoughts on hospitalization in the event of acute illness. Nora said *Yes, then I think I want to be admitted (to the hospital).* When the nurse offered the possibility of treating the illness at the nursing home, she said *No, then I would like to stay here.* The residents’ answers to questions on end-of-life treatment were often vague and inconsistent. For example, when a physician attempted to reach a common ground concerning end-of-life treatment, it was hard to know precisely what had been agreed, as this excerpt illustrates:

Aurora: I spoke with you about it once.

Physician: Yes, it regards us being active and treating you, depending on the situation.

Do we have an understanding?

Aurora: Yes.

**Planning for end-of-life care – often not on the residents’ agenda**

All four residents asked claimed that they did not often think about and were generally not preoccupied with end-of-life issues. Residents generally trusted their health care personnel to make sound decisions for them, claiming they knew them well. Lovise said she was done
thinking about illness and instead focused on living in the moment after recuperating from bad health. Some residents thought of dying as a natural, seemingly unchangeable, process. Nora said *it (death) has to come... it is a natural thing*. Aurora stated that she wanted to live as long as possible. However, when the physician asked if she had any thoughts on her future medical treatment she replied *No, I haven’t. Because I take it one day at a time. So I can’t respond to that*. Lovise was asked if she had thought about what she wanted at end of life *No, I haven’t... that day will come no matter what, it could be tomorrow, it could be in ten, twenty years. That’s life and I don’t have any thoughts about it... because when life is over, that is the time you had.*

**Cognitive impairment**

Conversations were hard to follow when residents had cognitive impairment, because of lack of focus or incoherent talk. Despite the cognitive impairment, relevant information could still be gathered from conversations. While observing, the researcher felt the responses of two residents had limited value. However, in reading the transcripts, it became apparent that relevant information could be provided by the residents, although easily missed – necessitating a good listener. When asked about her thoughts if she was to become acutely ill, Mille’s answer was hidden in an incoherent chain of thoughts. She replied, *for the time being, I don’t know...* Then she talked for several minutes without interruption about other, non-related topics. Her monologue ended like this:

> And then he [her brother] disappeared. Gone. Hasn’t shown up since. And then it was that about that and I hadn’t paid them, but it helped me and my family so it didn’t become a greater burden, but I will never forget that sight. Poor boy, oh well. **That’s what I’m thinking of, to have just as calm a departure as he had (been) given. I don’t need more.** [Bold added] People have so many kinds. I dreamt of my mom and dad once too. Do you care to listen?
Lack of relevant information

Sometimes relevant information about treatment options was lacking, which can be a threat to informed consent and involving residents properly. For example, when a physician asked the next of kin for their opinion on abstaining from cardiopulmonary resuscitation, they failed to provide further information on prognosis and what the treatment entails.

Uncertainty

Some next of kin indicated that they had not discussed the resident’s preferences for end-of-life care with them, leaving uncertainty as to what the resident’s preferences were. However, uncertainty about resident preferences was not necessarily avoided, even when the resident had communicated preferences to next of kin. For example, previous statements by the resident could provide direction, although not a clear answer, as to what the resident would want in their future medical treatment. Previous statements made only one next of kin remain uncertain about the resident’s treatment preferences going forward.

DISCUSSION

The staff succeeded in actively involving cognitively impaired nursing home residents, after a whole-ward approach (Gilissen et al., 2017) to implementation of advance care planning. Residents were the focus of conversations, residents elicited relevant preferences to health care personnel and next of kin gave valuable support to present residents during conversations. In addition, residents’ preferences were the focus of ACP conversations also when not present. However, important challenges related to ACP in these nursing homes were: vagueness of residents’ preferences, planning for end-of-life care often not on the residents’ agenda, cognitive impairment, the lack of relevant medical information provided by health care personnel and the uncertainty among next of kin as to residents previously reported preferences.
Our study indicates that, following a whole-ward approach to implementation, involving residents with cognitive impairment in ACP is possible and beneficial. More patients with cognitive impairment or reduced decision-making capacity can contribute to (T. J. L. Sævareid, Thoresen, Gjerberg, Lillemoen, & Pedersen, 2019) and benefit from ACP than previously assumed.

A major finding from this study was that, even when residents talked incoherently and had trouble focusing, important insight into their values and preferences were revealed. However, in these situations, a vigilant listener with effective communication skills is essential to spot residents’ values and preferences. Our findings are comparable to those from another study, older people with dementia in nursing homes have been described to be able to express preferences in most interviews, although not all wanted to be specific about future care (Goodman, Amador, Elmore, Machen, & Mathie, 2013). Residents’ ability to participate may be unknown before trying to include them in ACP. Therefore, our findings justify at least attempting to involve residents with cognitive impairment in the ACP process.

Supported decision-making (Devi et al., 2011) contributed to enabling these residents to participate in their future treatment-related decisions, which is in line with the ideals of patient-centered dementia care (O’Connor, Purves, & Downs, 2009) and guidelines (Piers et al., 2018). Enabling persons with dementia to participate in ACP is recommended (Piers et al., 2018; Rietjens et al., 2017) and supported by our findings. In general, to determine whether a resident is capable of participating in ACP, we have to engage with them. Moreover, excluding residents with questionable or reduced competence and/or next of kin may make ACP unattainable for most nursing home residents. Finally, failing to include residents with reduced competence in medical decision-making violates their human rights (Devi et al., 2011).
Involving residents in ACP, as described in this study, aligns with the ideals of discourse ethics (Bohman & Rehg, 2017) and principle-based ethics (Beauchamp & Childress, 2019). Including those affected by the decision and capable of making relevant contributions, an equal voice among participants, being free to speak and not being coerced (Bohman & Rehg, 2017) are among those ideals. Nevertheless, principle-based ethics has been criticized for being too rationalistic in its views on the concept of autonomy (Mackenzie & Stoljar, 2000), although principle-based ethicists state that “people’s actions are rarely, if ever, fully autonomous” (Beauchamp & Childress, 2019). Instead, feminist perspectives contend that patient preferences will always be influenced by the network of dynamic relationships they are a part of (Donchin, 2000) and thus promote relational autonomy (Mackenzie & Stoljar, 2000). In line with our findings, vagueness and uncertainties are inherent in ACP (De Vleminck et al., 2016; Tulsky, Fischer, Rose, & Arnold, 1998). We have described the important role played by next of kin in supporting patients during ACP conversations. Vagueness, uncertainty and the need for next of kin support in ACP suggest respecting resident autonomy should be regarded as broader than the resident’s individual capacities.

We believe our findings support that a whole-ward approach to ACP may contribute to a changed care culture and that implementation support has a great impact on such changes. Indications in this study of a changed culture and resident-focused ACP conversations were corroborated through interviews of the participants observed in the present study (T. J. L. Sævareid, Førde, Thoresen, Lillemoen, & Pedersen, 2019). Furthermore, how to increase resident participation in ACP should be the focus of education and implementation support because nursing home physicians may be more intent on involving next of kin, rather than the resident, in end-of-life decision-making (Romoren, Pedersen, & Forde, 2016; L. Thoresen, Pedersen, Lillemoen, Gjerberg, & Forde, 2019).
Limitations

The findings discussed here suggest that a whole-ward approach to ACP is relevant and applicable to other cultures, due to, in part, an emphasis on adapting the ACP process to the individual resident and local practice (Lisbeth Thoresen et al., 2017). Individualized ACP is transferable to other care settings and nursing specialties and warrants further exploration through high-quality research.

Here, the observation of conversations enabled reporting and reflection on how ACP was actually carried out. These observations brought us closer to real-life practice and, therefore, we recommend this research method (Murdoch, 2016). Observation as a research method is little used in studies of conversations between physicians and patients/families (Fine, Reid, Shengelia, & Adelman, 2010).

Although one resident gave negative feedback on the nursing home experience, selection bias represents a possible limitation of this study as the health care personnel may have recruited residents and/or next of kin that were considered to be more positive toward the nursing home. Communicating to participant recruiters that any feedback is valuable for gaining knowledge may reduce any selection bias in future studies.

CONCLUSION

Based on the observations in this study, nursing home residents with cognitive impairment can actively and meaningfully participate in ACP, if the health care personnel actively listens. Persons with cognitive impairment should therefore be invited to participate in advance care planning. When possible and in line with the resident’s wishes, health care personnel should consider including next of kin in ACP to support the resident.

Several ACP-related challenges can arise in nursing homes. However, effective communication and person-centered care can be facilitated through the implementation of a
whole-ward approach to ACP and personal relationships between the resident, their next of kin and health care personnel.
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