


# “Even Though I Have Dementia, I Prefer That They Are Personable”: A Qualitative Focused Ethnography Study in a Danish General Hospital Setting

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Annemarie Toubøl<sup>1,2,3</sup>, Lene Moestrup<sup>1</sup>, Jesper Ryg<sup>2,3</sup>,  
Katja Thomsen<sup>3</sup>, and Dorthe Susanne Nielsen<sup>1,2,3</sup>

## Abstract

Patients with dementia often face challenges in hospital settings due to cognitive impairment. The aim of this study is to explore the encounter between patients with dementia and hospital staff, from the patient perspective. Focused ethnography guided the method for data collection and the analytical approach was abductive. The findings, based on 10 observations of patients with dementia and their encounter with hospital staff in a variety of hospital settings, reveal that staff often seem to not see the person beyond the dementia diagnosis. The findings also show, however, that significant moments are constantly negotiated during encounters between patients with dementia and hospital staff, moments which occasionally allow staff to see the patients to be seen as the person they are. A rethinking of the current dementia discourse is discussed, recommending attention to the two-way interaction between patients with dementia and hospital staff, and within this an awareness of a personable approach.

## Keywords

dementia, dementia friendly hospital, patient’s perspective, qualitative, focused ethnography, abductive analysis

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## Introduction

Hospital admissions for people with dementia are predicted to rise in the future (Lin et al., 2013), due to the increasing number of people affected by dementia (Patterson, 2018) and the associated comorbidity (Bunn et al., 2014). Patients with dementia benefit less from hospitalization compared with patients without cognitive impairment (Dewing & Dijk, 2016; Organisation for Economic Co-operation and Development, 2015) and their care tends to be suboptimal in somatic hospital settings (Innes et al., 2016). Language impairment among people with dementia can cause communication challenges with hospital staff, often resulting in poor interpersonal relations and misunderstandings, which can have crucial impacts on the patient’s behavior (Allwood et al., 2017). An observation study with a specific focus on the interaction between patients with dementia and nursing staff found that this patient group was often considered to be in either a “positive” or “negative” category, based on their behavior (Norman, 2006). In line with this, studies also show that hospital care of patients with dementia is often delivered with an embedded habitus, focusing on ward routines, medical procedures, and risk management (Digby

et al., 2017; Hung et al., 2017). Another study concluded that health care staff often miss opportunities to deliver person-centered care to enhance the identity, comfort, and occupation of patients with dementia and suggests that the encounter between patients with dementia and health care professionals needs attention to sustain personhood (Clissett et al., 2013). These missed opportunities, together with the focus on medical procedures and routines can lead to the patient feeling like a bystander in the hospital setting (Digby et al., 2017) and to feeling ignored, distressed, or uncertain (Cowdell, 2010). This is further acknowledged in a study of patients with Alzheimer’s disease that found patients wished that the health care staff knew them better and thereby understood and involved them more appropriately (Jensen et al., 2018). Not being recognized as a person and not being

<sup>1</sup>University College Lillebaelt, Vejle, Denmark

<sup>2</sup>University of Southern Denmark, Odense, Denmark

<sup>3</sup>Odense University Hospital, Odense, Denmark

## Corresponding Author:

Annemarie Toubøl, Health Sciences Research Center, University College Lillebaelt, 7100 Vejle, Denmark.  
Email: agto@ucl.dk



offered the same services as patients without cognitive impairment can be a result of this noninvolvement (Moyle et al., 2011).

To our knowledge, there is sparse literature on how patients with dementia experience the encounter with hospital staff in general and how their personhood is recognized in these encounters. To date, research has primarily focused on the relationship and interactions with health care staff only in specific hospital settings. Because these patients interact with a variety of different staff during hospital stays, we need to broaden our knowledge to include the encounters with a variety of groups (Featherstone et al., 2019). Furthermore, people with dementia historically have been omitted from research, which reveals an ignorance of their perspectives and views. The focus has generally been on the biomedical and neuropathological aspects of dementia, with only a narrow insight into life with dementia (Lepore et al., 2017). Sometimes the patients' perspectives have been presented from relatives' or care staff's points of view, which risks producing misleading conclusions by ignoring the direct views and needs of the person with dementia (Prato et al., 2018). Thus, it is imperative to include their perspectives (Digby & Bloomer, 2014) in shaping future services that are better adapted to the needs of this patient group. Inclusion of their perspectives can potentially enhance their autonomy and provide important insights into their views and needs (Rivett, 2017; Scerri et al., 2018).

## Aim

The aim is to explore, from the patient's perspective, the characteristics of the encounter between patients with dementia and hospital staff in a variety of general hospital settings.

## Method

This study was conducted with a qualitative design using focused ethnography (Higginbottom et al., 2013). Methodologically, the study is informed by the assumptions of a pragmatic approach regarding science from an empirical perspective. Human action should thus be understood in the light of meaning seeking and interaction, with a central focus on the relationship between method, theory, and observation (Brinkmann et al., 2014; Timmermans & Tavory, 2014). Knowledge is in terms of pragmatism activated through the use of "practical reasoning" (Brinkmann et al., 2014). In line with this, the abductive reasoning that informs our analysis emphasizes that discovery and justification of findings are connected in the construction of meaning (Timmermans & Tavory, 2012, 2014) The research question guiding the research process was as follows:

**Research Question 1:** How can we understand and conceptualize the encounter between patients with dementia and hospital staff in a general hospital setting?

## Theoretical Framework

To accentuate the encounters between participants and hospital staff, the theoretical framework drew on the work of Mattingly (1994, 1998) and her descriptions of therapeutic "emplotment" and healing dramas. Mattingly defines therapeutic emplotment as the creation of stories and story-like structures during and through social situations, where staff and patients interact and negotiate a "plot" through a collective subjectivity of information exchange (Tropea, 2012). Mattingly (1994) proposes that stories are better considered as tools rather than just something told, as an information exchange, because of the connection between how a "plot" is developed and maintained and how subjectivity unfolds over time. According to Mattingly, an important point is that therapeutic emplotment cannot be planned but is rather structured by unforeseen responses, often quiet and invisible at first sight (Tropea, 2012).

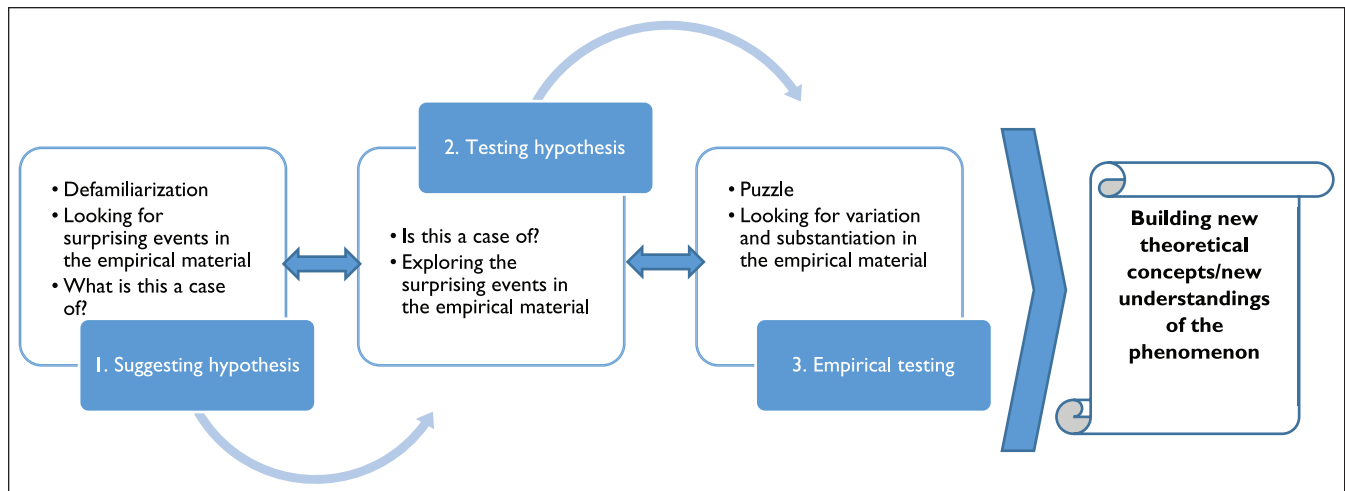
To further enhance the theoretical framework, we included Paul Ricoeur's philosophical approach to the word "recognition" to reach a deeper understanding of the encounter under investigation. Ricoeur identifies three semantic stages in which recognition moves from an intellectual form to an ethical understanding: (a) recognition as identification, (b) recognizing oneself, and (c) mutual recognition. He emphasizes that the second stage, recognizing oneself, bridges the gap between being seen as a thing (recognition as identification) or being seen as a person (mutual recognition) (Ricoeur, 2005). By recontextualizing this philosophical angle, our framework aims to give voice to how different understandings of recognition could thus play pivotal roles in the social situations observed in this study.

## Setting and Recruitment

The hospital where the study took place is a part of a university hospital in Denmark and with approximately 1,600 employees. A range of specialties are represented, with diversity in professions and job functionalities. Through gatekeepers at inpatient wards and outpatient clinics, patient participants were identified and purposefully sampled over a period of 7 months (May 2018–November 2018). The gatekeepers were nurses or health care assistants who had responsibility for the participants. Annemarie Toubøl, who conducted the observations, regularly visited the wards and clinics and together with the gatekeepers, decided whether the identified potential participants fulfilled the inclusion criterion.

## Participants

Participants were included if they had a diagnosis of dementia of any type from early to late stage. No distinctions were made as to gender, age, or residency. Exclusion criteria were critical illness or life-threatening situations. Ten patients



**Figure 1.** The analytical process.

with dementia participated in the study, representing acutely admitted inpatient and scheduled outpatient statuses. The participants included were five men and five women aged 77 to 96 years. Three of the participants lived in care homes and the rest in their own homes, either alone or with a spouse. Demographics and health data were accessed through patients or relatives.

### Data Collection

A focused ethnographic approach was taken and the study structured to follow one patient at a time during the course of a hospital admission or outpatient visit. Focused ethnography allows for background knowledge on the part of the observer (Higginbottom et al., 2013), which was true here given that the observer is a trained nurse, though not a part of the clinical team at the study site. Short duration field visits are recommended in focused ethnography, which served the participants well due to their cognitive impairments, and aligned with the “fragmented” nature of work in a hospital setting (Kawulich, 2005; Knoblauch, 2005). In this study, observing multiple encounters with a variety of hospital staff in different settings was essential, as it provided an exceptional opportunity for insight into the perspectives of patients with dementia.

The patients were followed from 1 hour to 5 hours and 30 minutes. The observer was a passive participant in the situations and only participated actively if the safety of the patients was threatened or if the patients’ needs had to be met immediately and no hospital staff were available. Furthermore, informal conversations were conducted with participants during observations when their physical and cognitive condition allowed.

As the focus of the present study is the encounter between patients with dementia and hospital staff, we followed Atkinson (2015), who argues that in ethnography, the

encounter and the interactions are in the foreground as situations, and should not be reduced to the participants’ individual actions (Atkinson, 2015). To ensure that we emphasized the situation, we further turned to Spradley (1980), who enumerated nine dimensions of social situations: space, actor, activity, object, act, event, time, goal, and feeling. These dimensions served as a guide to comprehensively understand the observed situations (Spradley, 1980), and informed the use of the observation tool and the informal conversations. This ensured that the situational characteristics were captured systematically in all situations.

During observations and informal conversations, the observer wrote field notes. These were transcribed verbatim into anonymized coherent scripts by the first author, with expanded and rich descriptions of details as soon as was practicable after observation, with an awareness of the tendency to interpret and simplify (Hammersley & Atkinson, 2007). Transcripts were stored and accessed in a secured database.

### Analysis

The empirical material was analyzed by hand using the principles of abductive analysis (Timmermans & Tavory, 2014). The analysis consisted of three phases with an iterative movement between phases (Figure 1). First, the field note transcripts were scrutinized and initial coding and memo writing was performed, as was the search for patterns. A key concept practiced in this initial phase was defamiliarization, asking: “What is this a case of?” rather than assuming. This approach thus allowed for the discovery of surprising events and for testable hypotheses to be developed. Second, theoretical insights from Mattingly’s (1998) theory were used as sensitizing concepts, in line with abductive reasoning (Atkinson, 2015; Timmermans & Tavory, 2012, 2014). A connection was found between the theory of “healing dramas

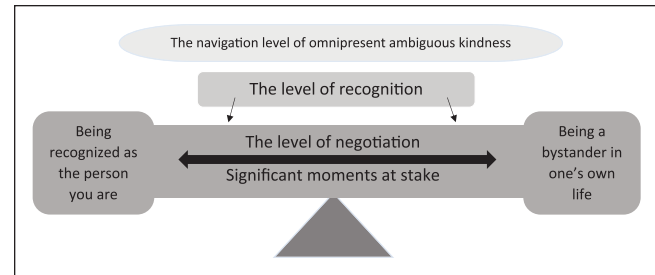
and clinical plots” (Mattingly, 1998) and the empirical insights from the coded memos from Phase 1. This guided the further exploration of the empirical material, rereading the ordered data while maintaining a tension between discovery and justification and utilizing the theoretical concepts (Mattingly, 1998) in detail. In this phase, the hypotheses were tested and “significant moments at stake” was discovered as an overall concept, and within this, the possible results of the social situations. Third, the transcripts were reread to ensure that variation occurred in and across the transcripts and that this variation adhered to the theoretical inferences. This was a way of empirically testing the second phase results. In this third phase, the transcripts were also revisited with an additional theoretical concept, namely the concept of recognition (Ricoeur, 2005). This was done to refine the analysis and to create a comprehensive understanding of how patients with dementia experience the encounter with a variety of hospital staff in different hospital settings. In this third phase, in the empirical puzzle of creating new theoretical insights, the “ambiguous kindness” emerged from the empirical data and was adopted as a significant, omnipresent component. The analysis was undertaken by Annemarie Toubøl, followed by continuous discussions and contributions by Lene Moestrup, Katja Thomsen, Jesper Ryg, and Dorthe Susanne Nielsen.

### Ethical Considerations

The study was conducted in line with the Helsinki Declaration (World Medical Association, 2013) and approved by the local hospital management and the Danish Data Protection Agency (18/14259). In accordance with Danish legislation, regional health research ethics committees were informed, and ruled that the study required no ethical approval (S-20182000-1). The participating patients were informed about the study verbally by Annemarie Toubøl and, if they were able to read, they were also informed in writing. Written consent was given by some participants. If participants were unable to give informed consent either verbally or in writing, close relatives were contacted and informed, and those relatives verbally provided a proxy consent. Given that cognitive impairment can be a factor in dementia, informed consent was sought on an ongoing basis (Higgins, 2013; West et al., 2017) with constant repetition of the reason for the observers’ attendance, if questioned. The hospital staff at observations were informed verbally and in writing and gave verbal consent. All participants were informed that they could withdraw at any time.

### Findings

In the iterative, abductive analysis, three levels were identified to conceptualize the encounter between patients with dementia and hospital staff: the level of negotiation, the level of recognition, and the level of navigation, see Figure 2.



**Figure 2.** The conceptualization of the encounter between patients with dementia and hospital staff.

First, as an overall concept and an answer to the research question that guided the analysis, the negotiation level illustrates that *significant moments are at stake* in the encounter. Significant moments are characterized by mutual subjectivity in the social situations and the attempted co-creation of a common goal. “At stake” illustrates how these significant moments are negotiated on an ongoing basis, resulting in a constant movement between success and failure. This is reflected in the concepts of: *being recognized as the person you are* and *being in suspense as a bystander in one’s own life*. These possible outcomes of the continued negotiation were dependent on how hospital staff recognized the patient. This is illustrated as the level of recognition. Finally, we outline the omnipresent premise of the *ambiguous kindness* expressed by hospital staff, which patients with dementia had to navigate. This last concept provides an enhanced understanding of the navigation level of the encounters between patients with dementia and hospital staff. In the following, illustrative excerpts and quotes are identified by participant number and data collection method if the quote is from an informal conversation.

### Significant Moments Are at Stake

The results of the analysis indicate that significant moments are under constant negotiation, beginning with invitations or opening gestures made by both parties, and from there unfolding in the social situations context of patients with dementia encountering hospital staff.

In the following excerpt, a patient is invited into a situation by a nurse who intends to help the patient shower. It illustrates how the patient and staff participant each adopted a different approach to the negotiation, but also that the responses were negative, keeping the significant moment at stake.

The nurse (N) comes in the door and says to the patient (P): “We think that you should have a bath.” The patient says that he does not like it, to which N answers: but we can see that it has been some time, and it is a good start to the day. The patient asks if they are monitoring that. No answer to that question. N leaves again, while saying: “In a little while the bathing patrol will come” (laughs to the patient). P sits in his armchair and says in

the air: "I don't know what it is." He tucks a blanket well around his legs. N comes again and has a student with him, who takes of the blanket. P says: "Uhh, now it's cold." N: "You will be glad after you've had it." P: "I don't think so—I'm not used to it—I bathe at home with soap and water." N: "SO! (loud tone, N and the student help P to stand up), and now we go to the bathroom together." P sighs loudly—"I don't know what this is," looking around questioningly. There is no response from the staff. (Patient 9)

This negotiation includes invitations or questions from both the patient and the nurse followed by repeated rejections. The shift in atmosphere is evident by the increase in vocal by the nurse after the humoristic approach seems to fail: The patient shows an attitude of resignation as his contribution with reference to his habits is ignored.

In most situations, shifts in atmosphere similar to the first example resulted from breaches in the linear course of treatment and care. Such moments could represent opportunities for development of a shared plot, depending on if or how the changed atmosphere was approached. The results of such negotiations were almost always immediately reflected in the patient's words and nonverbal signs, either talking or being quiet, smiling or ceasing to smile, active and attentive attitude, or passive withdrawal with a distant gaze. The latter was the most common, as significant moments often seemed to fail despite the pervasive exchange of invitations and questions in these situations. Significant moments that did unfold were easy to identify as the feelings expressed spoke for themselves, as in the following excerpt with the same patient from above:

The patient (P) is lying in his bed after a morning visit to the toilet. A physiotherapist (Physio) comes in and sits on the side of the bed and tells the patient that he would like to help him to go out for a bit. The patient says nothing, looks at the Physio questioningly and says: "You are are proper chap." This is laughed at by both. Physio asks about the patients housing and the patient difficulty answering this precisely. He says, for example: "It is difficult to answer exactly—it depends on . . ." He cannot find the words. Physio says: "It is because I want to know how you live so you can manage when you get back home." P says: "When I get up I am small in relation to you—no, I am not going anywhere" (pulls the duvet up over himself). Physio: "Will you go with a chap such as me—the big one and the small one?" (smiles and reaches his hand out to the patient). P: "Yes, you have humour (laughs and helps to stand up)—will I get to go home?" Physio: "Yes, we will have a fun walk and work so that you can go home" (After this the patient agrees and they go out together into the hallway, the patient smiling and talking). (Patient 9)

As in many other situations observed, this shows that the patients often express resistance to some extent and that the situations contain an exchange of invitations. As this significant moment emerges, despite initial resistance, the physiotherapist grasps the patient's story and lets it direct the

negotiation of the clinical task through a mutual recognition. In line with Mattingly (1998), it is clear that the physiotherapist has reflected on what story he is a part of.

### *Being Recognized as the Person You Are*

When significant moments appeared, the patients' stories were often used as tools in the negotiation either verbally or as objects, in terms of revealing the person beyond the clinical diagnosis. In these situations, the negotiation was characterized by a shared path, in which the patient's presented self was included in the clinical task or contact. These moments were breaches in the ordinary course of provision of care and even if they were temporary, the patients appreciated them, judging by their behavior, characterized by, for example, laughing, calmness, or obliging facial expressions. One patient expressed the approach he preferred to see adopted by the hospital staff: "Even though I have dementia, I think it's best that they are personable" (informal conversation, Patient 3).

At an outpatient clinic, one participant with Alzheimer's disease awaited a colposcopy in a private room. The situation refers to a significant moment in the course of care and treatment where the patient's story is addressed in the clinical situation, resulting in a human equality that influences both how the experience is manifested and how the underlying implication can be understood.

The patient (P) is alone in a bed-unit, keeping a close eye on what is going on in the hallway whenever there is a rattling of equipment or something passes by. Alternately, he sits in a reclining chair or walks restlessly around with a searching look. A nurse (N) comes in with instruments to insert an intravenous cannula. N asks him to sit down in the chair, "So they can get it over with." He sits right on the edge of the chair with a questioning look. The things are taken out and N starts talking about every day topics. P looks at the bridge, which can be seen from the window and they talk about traffic and bridge building. P tells with a little difficulty that he used to help building bridges and N asks about it. P cannot find the words in his answer and N helps the patient by asking if he was mostly on land, as P says he was not on the bridge during its construction. P lights up, smiles, laughs a bit and wants to talk about it. He slowly slides all the way back into the chair and sits relaxed with his legs crossed while the intravenous cannula is inserted. He remains seated when N has gone and seems to enjoy the view (smiling and looking attentively while nodding his head). (Patient 1)

As typical in these social situations, two sets of foci were present: the medical focus represented by the hospital staff and the everyday life story focus represented by the patient. There is a tendency for the medical focus to dominate; however, this dominant focus is capable of involving the patient's perspective, as seen here. The excerpt above illustrate a situation interrupted by significant short moments in which the patient's contribution is meet as an acknowledged input in

the social situation. As an evident symbol of how the atmosphere changes, the patients become relaxed and open-minded, a mood that facilitates sharing stories as tools in the mutual partnership. The patient is recognized in an ethical way: attention is given to the story that is an important part of him as human being, a moment of recognition that shows it does not matter whether he remembers exact details about the bridge.

In this study, as in most hospital settings, the majority of task focus on the body, but through the course of care and treatment some situations provided insight into the patients' perspectives and stories through objects that were of great importance to the patient. These significant objects could play a pivotal role in the patient's effort to tell their stories and thereby to be recognized as the person they are. On an orthopedic ward, a patient admitted with a hip fracture needed help completing everyday tasks such as bathing and mobilization:

The patient (P) has asked for her brush all morning during all the various actions that have taken place and has repeatedly tried to fix her hair by running her hand through it and smoothing it out. She now sits in the chair by the bed and tries to open the bedside table, but with no luck. I (the observer) open it for her, so she can look in. I take out her brush and ask if it's the one she's looking for. "Yes," she says and sighs. She arranges her hair and puts clips in and smiles contentedly and dabs her mouth with a napkin (as one does after applying lipstick). She drinks from the coffee that has sat there since breakfast at 8:10 am (the time is now 10:50 am). When the nurse assistant (NA) comes in to attend to another patient, she notices her hair and says: "Don't you look good with your hair done (smiling), you have a good place there by the window. It is good you have been mobilized." P says: "Yes, it is a nice coffee (smiles, folds her hands in the lap)—I'm waiting for lunch (she did not eat the breakfast and has told the staff on being asked earlier in the morning that she has no appetite)." This is the first time she has smiled at the staff during the entire morning procedure. (Patient 5)

This very short moment of significance illustrates that an important object like a hairbrush can be a fundamental factor enabling a connection to the patient's story. The acknowledgment from the nurse assistant results in the feeling of being recognized as a person. This situation illustrates Mattingly's (1998) point that a shared direction relies on becoming a person with attention to how the patient prefers to be seen rather than being a person belonging to a category of hip fracture patients.

### *Being in Suspense as a Bystander in One's Own Life*

In social situations, observations revealed that the negotiation of significant moments often resulted in experiences of being "in suspense." The analysis showed that this was twofold, both a sense of unsuccessfully searching for an overall

picture of the situation and a sense of being ignored as a person.

In many situations, the patients asked the hospital staff what they were going to do or expressed that they did not know what was going on or what was going to happen to them. These requests were typically answered by the hospital staff in general terms with reference to the clinical procedures or the patients' course of admission, without assuring that the patients understood these responses, leaving the patients as bystanders.

The following excerpt shows how one patient tried to get an overview of the situation while a nurse helped her return to her bedside. The patient expressed a wish for rest time in bed which was ignored by the nurse, who instead responded with reference to the patients' clinical status:

Patient (P) looks at nurse (N), sighs loudly and says: "Well, but I'm tired. I usually like to rest a little—what should I do in the chair?" No response—N helps P into the chair and leaves with the comment: "You are doing well—you are only on day two" (touches the patient on the shoulder). P: (while staff are on their way out) "I'm tired, I don't know what to do." The patient then sits in the chair and repeats folding a napkin countless times as she looks blankly in front of her and then falls asleep. (Patient 6)

A similar situation occurred when a patient repeatedly asked for information about discharge:

The patient (P) asks when he can go home again (he has just arrived on the ward). That question is not answered, but the patient is told to change, which is said with an indulgent smile and pat on the shoulder. The patient asks again after a short time and the nurse (N) answers: "First you have to have your treatment." After the treatment the patient asks again and the answer is: "Now you have to eat a little first. The patient walks around the room uneasily, not eating much of his food." (Patient 1)

These two excerpts illustrate that the negotiation of a significant moment is difficult to accomplish when the patient's attempts to understand the situation are disregarded in favor of what the hospital staff consider to be essential. The characteristics of these situations show that neither the patient nor the hospital staff succeed with their invitations to negotiate with the other party. This seems to result in a neglect-based negotiation where the patients are kept in suspense, not given the information they need that would help them understand the situation, while the hospital staff repeatedly refer to the clinical context. The feeling of being in suspense is observable in the restless behavior and passive occupation.

The sense of not being seen as a person, and of being kept in suspense, appeared in several situations in the empirical material and the analysis revealed great variance in this. The patients often tried to invite the hospital staff into their story as they referred to objects, interests, habits,

significant events, or signs that were present or associated with the situation and that could help them express themselves. Nevertheless, these invitations were often not seen or accepted, or were outright rejected by the hospital staff through ignoring the patient's words. The observed experience of being in suspense tended to depend on whether the patients were recognized as able to communicate about the clinical tasks in question, and thereby able to contribute on equal terms with the hospital staff. This recognition mode seemed to be a determining factor in the negotiation of significant moments that did not succeed, as the points of references of crucial importance to the patients were ignored.

The analysis cannot reveal whether the patient reactions were a result of the unfamiliar surroundings. The analysis does, however, show that patients displayed restlessness, agitation, and passive resignation often turning away from the situation. They did so when they felt in suspense as a result of the hospital staffs' focus on clinical goals.

### *Ambiguous Kindness*

The omnipresent kindness of hospital staff appeared in all situations where patients with dementia were in a constant negotiation of significant moments with hospital staff. This was also clear in the informal conversations with patients: They experienced kindness and appreciated it: despite this appreciation. However, both observed situations and informal conversations revealed the ambiguous nature of such kindness as an ambiguous kindness. Although there were smiles, gentle touches, talking, responding, and informing, there was also evasiveness observed through silently performed clinical tasks, nonresponsive attitudes, or responses given in general terms, such as "it can be hard to understand" or "I know it is difficult for you to be in the hospital." The kindness thus seemed to be an accessible gesture, but it was followed by ignored questions, the patient could feel excluded, as a bystander in their own situation. The patients expressed that kindness was both appreciated and exclusionary: "Yes, they are nice here, but they don't know me" (informal conversation, Patient 6). Another patient expressed, "They do their best, but I don't know what to do" (informal conversation, Patient 2). The ambiguous kindness did at times reveal an inclusive path, with the patient's story attended to with additional consideration for their dementia as a potential complication for the negotiation of significant moments. This inclusive approach provided easy access to negotiation for the patients and, as expressed by one patient, this was the ideal approach, as it contained both kindness, space for personality, and acceptance of the cognitive impairment:

It is important that you are met with kindness and I prefer that we are in familiar terms, but also that they know what's wrong with me, i.e. dementia and take this into account—I'm not so quick anymore (points to his head). (Informal conversation, Patient 3)

## Discussion

The overall concept in our findings around the significant moments at stake calls urgently for an improved focus on the *encounter* between patients with dementia and hospital staff, and within this to create opportunities to focus on significant moments in hospital settings. In line with a heightened awareness of the encounter, Smebye and Kirkevold (2013) state that the discussion of person-centered care and how it is delivered in care practice should focus more on the *relationship* as a fundamental factor. They argue that person-centered care as a direction for care can confuse the understanding of whether the person with dementia or the care staff is the expert in the situation. This can result in an overlooked opportunity to negotiate in a complementary, mutual way that could hold the patient's fragmented self together (Smebye & Kirkevold, 2013). Our findings illustrate that person-centered care is challenged in hospital settings, as patients with dementia are often met by a staff-dominant approach that involves either expectations of cooperation, with no attention to the dementia diagnosis, or the assumption of an inability to cooperate precisely because of the dementia diagnosis. As exemplified by ambiguous kindness, we observed that hospital staff often responded to bodily language with silence, while smiling, resulting in ignoring the sense of self expressed by the patient. This led to a suspension of the experience of being recognized as the person you are and thereby someone with their own coherent story that continues as a coherent element despite the cognitive impairment.

Our findings, however, indicate that negotiation with patients with dementia in a variety of situations *can* result in the patients experiencing being recognized as the persons they are. In line with Kitwood's (1997) description of the person-centered approach, an accessible way of reaching the person is by simply listening to their story in everyday situations: positive person-centeredness is the concept of being recognized as the person you are, indicating exactly what patients with dementia would benefit from. The positive situations illustrated in our findings were often unforeseen, but unfolded when patients and hospital staff constructed a common story while embracing their own goals and intentions. When a patient's personal story was mutually recognized, our results showed that it eased the patient's ability to negotiate—because it validated his or her own self. The maintenance of a sense of self is also acknowledged in other research on how the "self" or selfhood is constructed in cooperation with others and that the social context influences how the self is expressed and perceived (Hedman et al., 2016). In addition, the past can also be crucial to bring to the forefront to revitalize a sense of self in people with Alzheimer's disease (Hedman et al., 2016). At the same time, the possibility of being recognized as the person you are is illustrated as an effort that requires awareness from hospital staff. This is supported by another Danish study, discussing the complexity of

including the person with dementia and his or her own story when providing care, however, it is a goal within reach to improve care in an acute care setting (Jensen et al., 2018). In addition, Clissett et al. (2013) concludes in a study of an acute hospital setting, that there is a tendency in hospitals to de-emphasize person-centered care, resulting in missed opportunities to support and sustain personhood in patients with dementia. These authors suggest a future focus on the encounter between these patients and hospital staff because of the potential to enhance a sense of selfhood in patients with dementia (Clissett et al., 2013).

Being a bystander in one's own life, as identified in this study, illustrates a concept subsidiary to the significant moments at stake and how the conflict between patient selfhood and hospital staffs' clinical agenda complicated the possible significant moments. In addition, the process of negotiation was challenged by the patients' ability to make sense of the situations and thereby respond and express themselves in a timely and clear manner to match the language and tone of the clinical hospital setting. The omnipresent ambiguous kindness often came together with the hospital staff overlooking contributions made by the patients with dementia to the social situations, contributions which they offered as a way showing personhood. This ambiguous nature of such kindness is exemplified through the hospital staffs' friendly responses as a covered ignoring of patient inquiries or communication. This aligns with the findings from Norman's (2006) observation study, in which she points out that nursing staff rarely encourage patients with dementia when it comes to helping them express themselves. She found that nursing staff often perceive the patient's attempt to portray themselves as problematic behavior, akin to wandering and resistance (Norman, 2006). The level of recognition as a determining factor in the negotiation of significant moments in our findings could, at times, be viewed as a pre-determined understanding that patients with dementia are not expected to be able to negotiate and are thereby neglected as negotiators. This concurs with similar findings from a qualitative observation and interview study of patients with dementia and nursing staff in acute hospital settings that showed that the hospital system does not leave much room for person-centered care. Even though nurses strive to deliver person-centered care, there is a tendency to treat the patients with dementia as staff have always treated patients with dementia: without concern for personhood (Cowdell, 2010).

Bringing personhood to the forefront, as our findings illustrate, is complex and can be viewed as a challenge in hospital care and treatment of patients with dementia. Several barriers exist, such as difficulties in the maintenance of social identity and the apparently prioritized medical focus. This can result in the perpetuation of patients with dementia in a "malignant" position, which Kitwood (1997) opposed 20 years ago. Previous research has found that malignant positioning is a result of viewing people with dementia as unable to remember, cooperate, or understand (Featherstone et al.,

2019). Therefore, the overall concept of significant moments at stake concur with the idea that it is time to discuss the discourse around dementia. The current dichotomized discourse in the complex experience of dementia is evident in our findings as well. Patients are regarded as participating only insofar as they follow instructions without resistance: Otherwise, they are regarded as only having the dementia diagnosis, unable to cooperate. This challenged the patients with dementia during hospitalization, as they were trapped in "the discourse of tragedy or living well" as described by McParland et al. (2017). These authors also advocate for a new discourse that accepts the incongruity of the complex condition of dementia arguing that this new discourse should include both taking into account the difficulties inherent to cognitive impairment in care and treatment and at the same time respecting the human being beyond the dementia diagnosis (McParland et al., 2017). This is further acknowledged as a turn toward a positive dementia discourse by de Vugt and Dröes (2017), who argue that the discourse of dementia must focus on living well with dementia including respect for the losses and difficulties that challenge these people, thereby avoiding depersonalization and threats to dignity.

## Methodological Considerations

By illustrating an observed patient perspective that has not previously been described in such detail, our results depict a neglected potential in dementia care and treatment in general hospital settings. Our findings contribute to the existing knowledge on patients with dementia in hospital settings with new insights and an enhanced understanding of the encounter between these patients and hospital staff.

The process of recruitment of participants in this study presented dilemmas. Some gatekeepers acted overprotectively and denied some individuals with dementia the opportunity to choose whether to decide to participate. Furthermore, recruitment was influenced by how gatekeepers perceived the research and their personal views about the research project. This is a condition that the researcher must accept given the necessity of gatekeepers in the recruitment process (Hellström et al., 2007) and illustrates that assisted selection of participants can contain elements of bias.

Our study involved only 10 participants; however, the collected data were sufficient to gain insights into the characteristics of the encounter between patients with dementia and a variety of hospital staff, because the rich and variant data from diverse situations allowed for the creation of a conceptualization of these encounters (Mason, 2018). However, the results of this study may have been different with younger participants. Furthermore, the results might have revealed different insights if the sampling strategy and the aim of the study focused on a specific stage of illness.

Observation was a valid method to learn from the perspective of persons with dementia, although there can be some uncertainties as to the true perspective of the person



and thereby the results can include biased information (Hung et al., 2018; van Baalen et al., 2011). To mitigate this uncertainty, the first author carefully distinguished the terms used by the participants and the observer's own terms in the field notes with reference to finding out what the observed individuals know (Hammersley & Atkinson, 2007; Kawulich, 2005). However, systematic observation can be the most promising method to describe patient experiences of hospitalization, as patients with dementia often express their experiences not only verbally but also emotionally, as reflected in body language. In addition, observations give voice to these vulnerable patients despite the memory loss and limited vocabulary common in dementia (Goldberg & Harwood, 2013). Furthermore, observation makes it possible to achieve an overview of a network of social situations (Spradley, 1980) that would otherwise be fragmented into activities with few participants, limited in time and scope (Kawulich, 2005; Knoblauch, 2005). Nevertheless, there is no consensus on how or whether to involve people with dementia in research, which points to a need for future focus on such guidelines (West et al., 2017). Authenticity and trustworthiness were ensured throughout data collection and the initial analysis through the use of the observation tool inspired by Spradley (1980). This tool guided the systematic focus on factual circumstances and how they were reflected in participant behaviors. An example is the observation of the feelings expressed by participants with dementia in the encounter with hospital staff, as this led to the central findings and at the same time represented a situational closeness.

## Conclusion

This study identified some evidence of "significant moments" when patients with dementia encounter a variety of hospital staff in hospital settings. Furthermore, these moments are particularly momentous as they can contribute to patients with dementia experiencing that their personhood is acknowledged. Despite the fact that patients with dementia have the ability to negotiate significant moments, it was clear in our study that this potential was often neglected. Our findings suggest a need for new approaches to person-centered care for these patients in hospital settings. The approach should focus on the two-way interaction, recognizing that despite the character and time span of the encounter, there is potential to support patient selfhood. Finally, we advocate for a new dementia discourse that acknowledges the fact that being a person and a patient with a dementia diagnosis are not contradictory "either/or" conditions. Caring for hospitalized patients with dementia requires awareness to support and respect the person's ability to be a patient.

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## ORCID iDs

Annemarie Toubøl  <https://orcid.org/0000-0003-4794-8862>

Dorthe Susanne Nielsen  <https://orcid.org/0000-0002-3954-7551>

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### Author Biographies

**Annemarie Toubøl**, Ph.D. student, MScN, RN. Employed at University College Lillebaelt since 2010 as a senior lecturer. AT is doing a Ph.D. study with a focus on dementia friendly hospitals and affiliated to the Department of Geriatric Medicine, OUH, Svendborg

and Department of Clinical Research, University of Southern Denmark.

**Lene Moestrup**, Ph.D., MSch, RN. Employed at University College Lillebaelt as a senior lecturer and researcher at the Department of Health Sciences Research Center. LM's current research has a focus on dementia.

**Jesper Ryg**, consultant, Ph.D., is associate professor and head of Geriatric Research Department of Geriatric Medicine at OUH and Department of Clinical Research, University of Southern Denmark.

**Katja Thomsen**, consultant, Ph.D. Employed at Department of Geriatric Medicine, OUH.

**Dorthe Susanne Nielsen**, Ph.D., Associate professor, Docent, RN. DSN is currently positioned at Migrant Health Clinic, OUH, Centre for Global Health, University of Southern Denmark, and Health Sciences Research Center, University College Lillebaelt. DSN's research concerns migrants and vulnerability.