Citation	Bryon, E., Dierckx de Casterlé (2012), 'Because we see them naked' – nurses' experiences in caring for hospitalized patients with dementia: considering artificial nutrition or hydration (ANH) Bioethics, 26(6), 285 - 295
Archived version	Post-print. Author manuscript: the content is virtually identical to the content of the published paper, but without the final typesetting by the publisher
Published version	http://dx.doi.org/10.1111/j.1467-8519.2010.01875.x
Journal homepage	http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1467-8519
Author contact	Bernadette.dierckxdecasterle@med.kuleuven.be + 32 (0)16 37 33 17
IR	https://lirias.kuleuven.be/cv?u=U0014889

(article begins on next page)

“Because we see them naked”—Nurses’ experiences in caring for hospitalized patients with dementia: considering artificial nutrition or hydration (ANH)

ABSTRACT

The aim of this study was to explore and describe how Flemish nurses experience their involvement in the care of hospitalized patients with dementia, particularly in relation to artificial nutrition or hydration (ANH). We interviewed 21 hospital nurses who were carefully selected from nine hospitals in different regions of Flanders. ‘Being touched by the vulnerability of the demented patient’ was the central experience of the nurses, having great impact on them professionally as well as personally. This feeling can be described as encompassing the various stages of the care process: the nurses’ initial meeting with the vulnerable patient; the intense decision-making process, during which the nurses experienced several intense emotions influenced by supporting or hindering contextual factors; and the final coping process, a time when nurses came to terms with this challenging experience. From our examination of this care process, it is obvious that nurses’ involvement in ANH decision-making processes that concern patients

with dementia is a difficult and ethically sensitive experience. On the one hand, the feeling of 'being touched' can imply strength, as it demonstrates that nurses are willing to realize good care. On the other hand, the feeling of 'being touched' can also imply weakness, as it makes nurses vulnerable to moral distress stemming from contextual influences. Therefore, nurses have to be supported as they carry out this ethically sensitive assignment. Practical implications are given.

INTRODUCTION

Dementia is a progressive neurodegenerative and ultimately fatal disorder. Unless another fatal illness intervenes, patients with dementia gradually lose cognitive and physical functions.¹ During later phases, these patients often develop serious eating problems,² requiring

¹ S.L. Mitchell. A 93-year-old Man with Advanced Dementia and Eating Problems. *JAMA* 2007; 298: 2527-2536.

² T.E. Finucane, C. Christmas, K. Travis. Tube Feeding in Patients with Advanced Dementia: a Review of the Evidence. *JAMA* 1999; 282: 1365-1370; E.L. Sampson, B. Candy, L. Jones. Enteral Tube Feeding for Older People with Advanced Dementia. *Cochrane Database Syst Rev* 2009; 15: CD007209.

clinicians to make a decision concerning artificial nutrition or hydration (ANH).³ ANH is a form of medical treatment in which nutrition or hydration is administered enterally or parenterally.⁴ ANH decision-making is clinically, emotionally, and ethically one of the most difficult dilemmas encountered in dementia care, as it deals with one of the most fundamental necessities of life.⁵

Providing nutrition and hydration has strong symbolic meaning for many families and healthcare staff.⁶ Feeding is often seen as a basic caregiving activity, whereas withholding food is associated with neglect

³ G. Bosshard et al. Forgoing Treatment at the End of Life in 6 European Countries. *Arch Intern Med* 2005; 165: 401-407; H.M. Buiting. Forgoing Artificial Nutrition or Hydration in Patients Nearing Death in six European countries. *J Pain Symptom Manage* 2007; 34: 305-314; P.T. Van Wigcheren et al. Starting Artificial Nutrition and Hydration in Patients with Dementia in the Netherlands: Frequencies, Patient Characteristics and Decision-making Process. *Aging Clin Exp Res* 2007; 19: 26-33.

⁴ D. Casarett, J. Kapo, A. Caplan. Appropriate use of Artificial Nutrition and Hydration – Fundamental Principles and Recommendations. *New Engl J Med* 2005; 353: 2607-2612.

⁵ H.M. Buiting et al. Forgoing Artificial Nutrition or Hydration in Patients Nearing Death in six European countries. *J Pain Symptom Manage* 2007; 34: 305-314; Mitchell, *op.cit.* note 1; M.R. Gillick. Rethinking the Role of Tube Feeding in Patients with Advanced Dementia. *N Engl J of Med* 2000; 342: 206-210.

⁶ Gillick, *op. cit.* note 5; Casarett et al., *op. cit.* note 4.

and abandonment.⁷ Furthermore, the most recent clinical evidence fails to support the effectiveness of ANH in patients with dementia and warns of potential adverse consequences.⁸ The inability of patients with advanced dementia to communicate their treatment wishes and the lack of or inadequacy of advance directives make such decisions even more challenging.⁹

ANH decision-making involves making medical decisions, in which physicians have the final responsibility.¹⁰ According to Buiting et

⁷ R. McCann. Lack of Evidence about Tube Feeding -- Food for Thought. *JAMA* 1999; 282: 1380-1381; M. Ersek. Artificial Nutrition and Hydration. *JHPN* 2003; 5: 221-229; P. van der Riet et al. Palliative Care Professionals' Perceptions of Nutrition and Hydration at the End of Life. *Int J of Palliat Nurs* 2008; 14: 145-151.

⁸ Finucane et al., *op. cit.* note 2; Gillick, *op. cit.* note 5; Sampson et. al, *op. cit* note 2.

⁹ P. Triplett et al. Content of Advance Directives for Individuals with Advanced Dementia. *J Aging Health* 2008; 20: 583-596; M.E. de Boer et al. Advance Directives in Dementia: Issues of Validity and Effectiveness. *Int Psychogeriatr* 2010; 22: 201-208.

¹⁰ H.R. Pasman et al. Forgoing Artificial Nutrition and Hydration in Nursing Home Patients with Dementia: Patients, Decision-making, and Participants. *Alzheimer Dis Assoc Disord* 2004; 18: 154-162; H.R. Pasman et al. Participants in the Decision-making on Artificial Nutrition and Hydration to Demented Nursing Home Patients: a qualitative study. *J Aging Stud* 2004; 18: 321-335.

al.,¹¹ physicians discuss forgoing ANH with the nursing staff in 22% (Italy) to 76% (Belgium) of cases. Nurses find decisions concerning food and fluid intake to be especially complicated, because feeding patients is an important basic task for which nurses feel responsible.¹² A recent international review showed that nurses struggle in balancing ethical values—such as respect for autonomy, beneficence, sanctity of life, and dying with dignity—as they form their stance on whether ANH should be provided.¹³ Since the prevalence of patients with dementia is increasing remarkably worldwide,¹⁴ the delicate issue of being involved in ANH decision-making becomes extremely relevant for the nursing profession.

The existing literature on nurses' involvement in ANH decisions in severely ill patients (including patients with dementia) demonstrated that nurses experience several emotions such as guilt, frustration, sadness,

¹¹ Buiting et al., *op. cit.* note 5.

¹² Pasman et al., *op. cit.* note 10.

¹³ AUTHORS

¹⁴ C.P. Ferri et al. Global Prevalence of Dementia: a Delphi Consensus Study. *Lancet* 2005; 366: 2112-2117; O. Mashta. Number of people in UK with dementia will more than double by 2050. *BMJ* 2007; 334: 447; Alzheimer's Association. 2009 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2009; 5: 234-270.

and satisfaction.¹⁵ Whether nurses were pleased with the process depended on several contextual factors (e.g. ward culture, available support, doctor-nurse relationships) that could support or hinder their efforts to provide good care.¹⁶ Nurses who felt well supported coped better with emotional stress.¹⁷ Despite the ethical and emotional struggle they experienced, nurses felt they should play a role in ANH decision-making because they have close contact with the patients and their families. Nevertheless, they did not always feel that their contributions were valued.¹⁸

The available research allowed us to present only a rough sketch of how nurses perceive their involvement in ANH decisions.¹⁹ Several

¹⁵ AUTHORS

¹⁶ AUTHORS

¹⁷ V. Todd et al. Percutaneous Endoscopic Gastrostomy (PEG): the Role and Perspective of Nurses. *J of Clin Nurs* 2005; 14: 187-194.

¹⁸ E. Konishi, A.J. Davis, T. Aiba. The Ethics of Withdrawing Artificial Food and Fluid from Terminally Ill Patients: an End-of-life Dilemma for Japanese Nurses and Families. *Nurs Ethics* 2002; 9: 7-19; Todd et al., *op. cit.* note 17.

¹⁹ Only 2 articles identified in this review considered ANH decision-making in nursing-home patient with dementia. Pasman et al., *op. cit.* note 10; Pasman et al., *op. cit.* note 10. Though the majority of ANH

questions remain unanswered: What is the dominant process nurses experience? Of the contributions of others, which support and which hinder nurses? How do nurses cope with the emotions involved? Answering these questions will enable us to gain a more in-depth view, providing us with the insight that will help us to better understand hospital nurses' experiences and to help sustain them in this ethically difficult care assignment. Hence, the aim of the present qualitative study was to explore and describe how nurses experience their involvement in ANH decision-making for hospitalized patients with dementia.

decisions in patients with advanced dementia take place during hospitalization. S. Kuo et al. Natural History of Feeding-tube use in Nursing Home Residents with Advanced Dementia. *J Am Med Dir Assoc* 2009; 10: 264-270; J.M. Teno et al. Hospital Characteristics Associated With Feeding Tube Placement in Nursing Home Residents With Advanced Cognitive Impairment. *JAMA* 2010; 303: 544-550.

METHODS

Design and population

To present a rich and in-depth view of nurses' experiences, we chose a qualitative interview design inspired by the grounded theory approach.²⁰ We contacted all hospitals in Flanders (n=103) through their nursing directors. Ultimately, 22 hospitals agreed to participate. We asked them to complete a questionnaire about hospital characteristics and to select a contact person to oversee study communications. During the study, we purposefully selected nine hospitals out of the sample with the aim of gathering a wide variety of hospital characteristics (Table 1).

[Table 1 Hospital characteristics]

²⁰ B.G. Glaser & A.L. Strauss. 1999. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Jersey: Aldine transaction; J. Corbin & A. Strauss. 2008. *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. California: Sage publications, Thousand Oaks.

The contact person in each of the nine hospitals sought nurses who were (1) recently involved ($\leq$ one year ago) in a care process surrounding ANH decisions in a patient with dementia; (2) Dutch-speaking; and (3) willing to participate in an interview. Nurses fulfilling these criteria received verbal and written information and were asked to complete a questionnaire about their personal characteristics and experiences with ANH decision-making processes. We received 74 completed questionnaires. Initially, on the basis of their questionnaire, we purposefully selected nurses to interview with the aim of obtaining a sample with diverse personal characteristics and experiences with the subject matter. Later – using theoretical sampling - we selected nurses more specifically out of the received questionnaires, based on heightened insights gained through interview analysis. As such data collection and analysis occurred simultaneously. Ultimately, we interviewed 21 hospital nurses (Table 2).

[Table 2 Nurses' personal characteristics]

Data collection

We performed 21 semi-structured interviews (April 2008 - June 2009). We asked each nurse to relate his/her experiences when ANH was considered for his/her patient with dementia. The interview guide was based on a literature review,²¹ existing interview guides of the research team (ANONYMOUS), and discussions with the research team. It was refined throughout the research project. All interviews were conducted by the same researcher (ANONYMOUS), and were audiotaped and transcribed verbatim with the participants' consent.

Ethical considerations

Our institute's Ethics Committee approved the research protocol. All participants received verbal and written information; the informed consent procedure was respected. The anonymity of participants and institutions was carefully maintained, and all data were treated confidentially.

²¹ AUTHORS

Data analysis and trustworthiness

Data collection and analysis occurred simultaneously and systematically. A substantive reflection was formulated for each interview, in which important concepts related to the nurses' experiences were grouped into categories and subcategories. Developing patterns were continuously verified against newly collected data, in a constant forwards-backwards wave fashion. The final step involved the formulation of the 'story line', which was re-verified against all interviews.

Method triangulation was reached by going back to the 74 questionnaires we received after analysis of all interviews, to validate the concepts we developed in light of the nurses' answers to these questionnaires. Furthermore, trustworthiness was ensured by meticulously maintaining an audit trail and by detailing the research process and the decisions made.

To the greatest extent possible, we identified and bracketed previous knowledge and researchers' assumptions. All authors (ANONYMOUS) read all the interviews and regularly discussed the findings. In addition, a multidisciplinary team of independent experts

read the raw data and assessed the analysis we had already performed.

Data management was supported by QRS NVivo 8.

RESULTS

The findings reported here come from a larger study concerning nurses and the care that surrounds ANH decisions in hospitalized patients with dementia.²² In the first part of this study, which examined nurses' involvement during the ANH care process, we found that nurses are closely involved and fulfil diverse roles.²³ Despite this diversity, their involvement was characterized by one guiding principle: 'realizing good care' for demented patients.²⁴ By searching for the 'why' behind nurses' striving to give good care, we found that 'being touched by the vulnerability of the patient' was the central experience driving their willingness to strive for good care. This feeling can be described as encompassing the various stages of the ANH care process: the initial

²² AUTHORS

²³ AUTHORS

²⁴ AUTHORS

meeting with the vulnerable patient; the intense decision-making process; and the final coping process, which helps them reconcile this challenging experience.

Initial confrontation with the vulnerability of the patient

The feeling of 'being touched' arose from the first meeting between the nurses and the demented patient and increased in intensity as they got to know the patient better and as the patient's condition declined. The feeling of 'being touched' originated with the patient's vulnerable position. All interviewees noted the defencelessness, fragility, and dependency of these patients. They empathized strongly with the patients and found it to be emotionally difficult to see them in this condition. This encounter left a deep impression.

'...I think, in the care that I give, participation and autonomy is very important because the patient's living environment became so small. They have to give up so much of their independence... For me it is very difficult to deal with that....' (9)

Through intense and long-term care contact, the nurses not only formed a picture of the patient's medical condition but also became acquainted with the patient as a person, notwithstanding the advanced dementia. One of the nurses conveyed this striking event into words: *'...we see our patients not only literally but also figuratively naked...'* (5). nevertheless, it is precisely this vulnerable dependency that shaped a strong but often wordless appeal to nurses to provide dignified care. In addition, nurses were affected by persistent signals from patients—the refusal of food, defensive behaviour, and apathy. Nurses interpreted these as indications of weariness of life and meaninglessness. The interviews revealed that the nurses felt responsible, as professionals, to respond to this appeal; they balanced how best care can affect the patient and were willing to take responsibility as professionals to respond to this need.

'... Because we are the ones standing most closely to the patients... We wake them up in the morning, we take care of them In their behaviour, you feel their emotions, eight hours a day... then particular things become clear after a while...' (10)

The interviews indicated that the nurses not only felt addressed as professionals but also as people. They put themselves in the patient's place and tried to imagine the patient's experiences. Many interviewees expressed 'being personally touched' by applying the situation to themselves or to their family, making the situation real and near. Indeed, empathy faded the distance between their 'professional self' as a nurse and their 'personal self' as a person. In addition, empathy enabled nurses to develop great concern about the well-being of the patient. Through personal involvement, each nurse experienced the ANH decision as an ethically sensitive decision.

'... For me that's a question of life... that concerns not only this patient and that patient, later, it also concerns me, perhaps ... Do I want to live that way?... What can I do in the future not to end up in such condition?... I would not want it...' (10)

Although all interviewees recognized the roles the physician and the family play in the decision-making, they also considered their own involvement as obvious, due to their intimate nurse-patient relationship.

According to the interviewees' perceptions, nurses are the ones who have most strongly heard the patient's request.

'... I think it is my responsibility (as one of those who daily cares for that lady) that when she comes in a condition where she can't express her will anymore... that you say: 'I cannot let that happen!' [ANH administration]... And that doesn't come from one single emotional impulse of the patient... It is the lady's whole situation that indicates: 'That does not have to be anymore'... And that you express that for her, because she is not able [to do so] herself anymore...' (19)

Going through an intense decision-making process

Because of 'being touched,' all interviewees were willing to try everything possible to achieve dignified care. Therefore, the nurses figuratively positioned themselves between the patients, on the one hand, and the physician, the family, and the nursing team, on the other hand. The interviews showed that these three actors greatly influenced

the nurses' experiences.²⁵

Between patient and physician

How nurses experienced the decision-making process depended on the extent to which the physician allowed them to actively participate. The physician's final decision also greatly influenced their experiences. On the basis of their patient knowledge, could nurses agree with this decision? In their eyes, did this decision respect the dignity of the patient?

Some interviewees stated that the decision-making process occurred in an open atmosphere and in close cooperation with the physician. Regular discussions took place during which the physician was interested in their opinion. In this open atmosphere, the nurses expressed feeling confident enough to question decisions. They told feeling appreciated and recognized for their specific expertise. According to the interviewees, they reflected on the decision-making

²⁵ Although in reality gradations exists and experiences varied within one case, we describe them - in front of the physician, the family and the nursing team- on the one hand, as positive, and on the other hand, as negative to simplify the reconstruction.

process with great satisfaction, because they felt that they met the patient's wishes.

In most of the reported cases during the interviews, such cooperation led to a mutually agreed upon decision. According to the nurses, the decision to withhold or withdraw ANH supported the dignity of the patient. The nurses received sufficient space to answer the patient's pleas and to give priority to his/her comfort and needs. Although this care was emotionally taxing, the interviewees told to feel touched positively by the intensity and even by the beauty of the process. The dominant feeling of the nurses in this scenario was satisfaction.

'... When I look back, I am very happy that the physician didn't administer ANH anymore. Actually, she was... a wreck of a woman, skin and bone... That is a strange thing to say, but in my view, it ended beautifully...' (6)

Other interviewees expressed the experience that the ward ignored their opinions and forced them into a subordinate position. Under these circumstances, the physician seemed – according to the

interviewees - to base the decision to start or continue ANH only on his/her medical opinion, or in some cases on that of the family, even though these opinions clashed with signals from the patient – as interpreted by the nurses. Because their intimate nurse-patient relationship enabled them to view the patient beyond his/her medical condition, the nurses were frustrated. They felt that they were not acknowledged for their specific expertise. Some nurses expressed powerlessness and anger: Although they were deeply touched by the patient's vulnerability and wanted to respond, they were unable to do so. Those interviewees told to feel excluded from the decision-making and as if their sole purpose was to execute tasks.

'... Maybe frustration... you work here every day, you try to do it as good as possible... and eventually they totally pass you by... Then I sometimes have the feeling: 'What am I actually doing here?'...' (11)

Some of the nurses showed resignation: Repeatedly 'crashing against a wall' caused them to lose their fighting spirit. This does not mean that they were not touched by the patient's situation; rather, they

became aware that all their efforts were of no avail.

'... You can always say it, but they don't take it into consideration. Actually they still have the feeling that they know what's best... and in the end, you give up...' (18)

According to the nurses, negative feelings peaked when the decision of the physician failed to fulfil the patient's request. Interviewees experienced conflict between the decisions and what they wanted to realize for the patient. They expressed this conflict by listing ethical values that they believed were pushed aside by the decision: respect for autonomy, mercy, beneficence, nonmaleficence, quality of life, and human dignity. Their message was unanimous: according to them, the patient's vulnerability was not respected; on the contrary, the patient was wronged. This conflict provoked several intense emotions like disbelief, indignation, frustration, anger, and disgust.

'... I no longer went in that room with pleasure. That life was prolonged, the person was suffering, the wound smelled bad...

This person was going to die, you saw that immediately! Why do they decide to start ANH?...’ (6)

The decision was put into question and condemned: Is this really necessary? What are we doing? For some interviewees, their lack of involvement in the decision-making made them more confused about the decision. Indeed, these nurses were unaware of the physician’s motivation behind the decision, leaving them with much vagueness and uncertainty.

Several nurses told feeling distorted, because they had to perform tasks that clashed with their values as human beings. This distortion occurred when the patient’s family approached the nurses with questions and concerns about the decision. Professionally, nurses considered it as an unwritten law never to express their doubts in front of the family, in spite of their own disapproval of the decision.

‘... I found that emotionally hard because you can’t question the decisions of the physician out loud in front of the family... And then you are standing there, you want to look after the patient, you want to look after the family... but it is about something you

can't agree with at all...' (7)

Nurses also experienced distortion when they had to perform tasks they did not agree with as a person. Some nurses struggled with conscientious objections and feelings of powerlessness and frustration. The inability to meet the patient's request was very distressing.

'... We had to restrain him ... That went very difficult... He resisted strongly ... Nevertheless, we administrated fluid... It was against our conscience... 'What were we doing?' That man didn't want to live anymore' (15)

Some interviewees reconciled the feeling that they wronged the patient by compensating: Although they carried out tasks against their conscience, they did so very tenderly and respectfully in order to lessen discomfort as much as possible. They wanted to make the best of it.

'... You work as a nurse with your philosophy... but I think I have separated that: I placed that tube eventually, but I placed it with more care and more love because I really had the feeling that I

was discomforting him... and I think I was even more concerned, more aware than [I would be] otherwise to try to avoid all discomfort...' (7)

Although interviewees were convinced that the decision went against the patient's pleas, some nurses were uncertain of whether they interpreted the patient's signals correctly. Does the patient really not want to eat, or is he unable to eat anymore? Would ANH help the patient? Nurses experienced internal conflict: being convinced about the decision versus admitting that one can never be fully certain about a patient's signs because the patient is incompetent and ANH outcomes are unpredictable. The next quote illustrates well just how unstable and fragile this 'certainty' is:

'... When I came back to the ward, he was doing better... So I had doubts: 'Maybe I was mistaken, maybe it was the right choice after all' [to administer ANH]... He was better, more clear-headed... So I thought: 'I was wrong'... But after three days, he went downhill very quickly, vomiting... Then

my first thought was, 'so all the same, I was right somehow'...' (17)

Between patient and family

Family contact and the family's attitude also influenced how nurses experienced the decision-making process. Was the nurse-family relationship distant or close? From the nurses' viewpoint, did the family respect the vulnerability of the patient?

Some nurses experienced family contact during the decision-making process as pleasant and open. Especially when family members shared their views, the nurses experienced cooperation with mutual support and understanding, even though such close relations were very intense and exhausting. According to the nurses, family contact increased in intensity and confidentiality as the patient's length of stay increased and as they became more acquainted with the family.

Because of their close relationship with and empathy for the family, the nurses experienced a feeling of 'being touched by the family's suffering'. However, when the family's opinion failed to match what the nurses saw as the 'best possible care' for the patient, the

nurses felt divided. On the one hand, they wanted to meet the vulnerable appeal of the patient; yet on the other hand, they were touched by the family's suffering and understood very well that some family members wanted to try everything possible to keep the patient alive. This enabled some nurses to reconcile using a less drastic form of ANH, like a subcutaneous drip. The situation was complicated further when the opinions of various family members differed.

'...the contact with his wife was much more intense... She can put her feelings into words, and you sympathize with her and ... you can't even imagine how difficult it has to be... to lose someone you know for such a long time... And you want to agree with her and say: 'Ok, just do it' [administer ANH]... But when I thought back about the patient, then I thought: 'Oh no, I can't agree with that!'... And that gives me such inner conflict....' (17)

Other interviewees described a distant, even hierarchical, relationship with the family. If the family's treatment opinions differed from that of the nurses, the nurses did not feel a positive commitment and empathy towards the family, rather they showed indignation and a

lack of understanding towards the family.

'... I only saw them when they arrived for that discussion.... And I found that really harrowing, because I thought: 'They are the ones who claimed that tube feeding'... Of course, you don't know what history they have.... Actually, you should not judge them... but...' (9)

Between patient and nursing team

Another factor influencing how the nurses experienced the decision-making process was the nursing team. Did the nursing team share the same opinion? Could the nurse express his/her questions and concerns within the team?

Regardless of whether the nursing team shared the same opinion, if open communication existed, the nurses experienced positive cooperation within the nursing team. Cooperative conversations stimulated the nurses to view the situation from different perspectives. According to the nurses, the nursing team acted also as a continuous

outlet for difficult moments; thus, the nurses found support and understanding from each other.

However, some interviewees experienced disagreements within the nursing team, so that groups of nurses formed different opinions about ANH administration. According to the interviewees this sometimes caused serious conflict, involving mutual indignation and incomprehension. Such circumstances hindered the process, because vagueness and confusion arose about what policy to follow.

'... I really felt anger for her indifference... how she shrugged her shoulders... It was like, 'Which socks will we put on him, oh if it has to be the red ones, then just do it'... Then I think, 'If they are indifferent towards something like that [administering ANH or not], then how does the basic care have to be?'... I may not think about that because then I get even more frustrated and powerless...' (17)

Trying to cope

In retrospect, some nurses viewed the process as positive, whereas others viewed it as negative. Even though the decision-making process was arduous in some cases, if the appeal of the patient was ultimately met – in the eyes of the interviewees - and if the nurses had contributed, they felt relief and satisfaction, a certain inner peace. Afterwards they were able to leave the process behind more easily, disassociating themselves from it.

it was difficult, but we made it... It turned out well; the family had good feelings about the care, and we tried everything possible... So afterwards when our patient died, we could closed it off... And a half a year [later], I don't remember this patient anymore...' (4)

To conform was laborious when the nurses felt that the appeal of the patient was not met. As the nurses were – in their eyes - unable to respect his/her vulnerability, several nurses even experienced guilt towards the patient.

'I still see him in front of my eyes, squeezing his lips, shaking his head, ... And if I think that I tolerated it, that they brought him to that hospital... a man totally confused... To let [them] poke a hole in his stomach [for gastrostomy], everyone messing around with that tube... And he didn't even know what it was... (17)

To deal with this confrontation during and after the process, interviewees mentioned several coping strategies like team evaluation, venting to trusted colleagues or family members, exercise, and keeping work and private life strictly separate. Nevertheless, some interviewees were touched so deeply as a person that, even months afterwards, they reflected back on the situation with discomfort. Some interviewees never got used to such situations, even though they had experienced these several times.

Other interviewees expressed that these feelings evolved after years: They went through a 'growth process', learning to distance themselves appropriately. They were 'touched but at a distance.' Although they were touched as a person, as professionals they tried to maintain distance in order to protect themselves and to remain able to perform their responsibilities.

'...I can leave that behind... It has to stay out of your private life, otherwise you can't maintain... It's something difficult: being involved and keeping a suitable distance... But if you get too interwoven, then you can't do this [for] all those years, then you can't mean anything as a caregiver...' (19)

After the patient's death, several nurses received expressions of gratitude from the family or were invited to the funeral. These expressions of appreciation were seen as positive confirmation of their involvement and as support, enabling them to deal with the situation and have closure. On the other hand, when the family was dissatisfied with the process, the nurses remained weighed down with an uncomfortable feeling.

DISCUSSION

Methodological considerations

Based on our review²⁶ and as far as we know, this is the first study to explore the experiences of nurses in the care surrounding ANH decisions in hospitalized patients with dementia. Strengths of this study are (1) rich and in-depth representation of nurses' perceptions; (2) sample heterogeneity, enabling us to capture a variety of experiences; and (3) several built-in strategies, ensuring trustworthiness.

Notwithstanding we set up our design very carefully, a possible way to improve validity would be the use of participant observation next to the questionnaires and interviews. Examining the decision-making process from another perspective, could have filled up the gap between what is said and written and what is done in real practise by the nurses.

²⁶ AUTHORS

Even though some participants agreed with ANH when patients showed signs indicating they would benefit from ANH, because of the family's viewpoint or hope the patient might improve, none of the interviewees fully supported ANH in patients with dementia. Thus, we do not have sufficient information on the experiences of nurses who are ANH proponents. This may contribute to bias. However, the rather negative attitude towards ANH in patients with dementia we observed is representative of Flemish nurses, due to palliative care implementation in line with ethical guideline development in Flanders.²⁷

Another source of bias relates to the specific cases the nurses chose to discuss in the interviews. We noticed that they talked about cases that touched them emotionally. To counter this bias, we specifically examined the 74 questionnaires we received to include nurses who had positive experiences with ANH decision-making processes (theoretical sampling). Moreover, we asked all the interviewees to compare and contrast the case they described in their interview with other cases in which they were

²⁷ AUTHORS

involved. This allowed us to unveil different scenarios in the nurses' experiences.

Discussion of the findings

Nurses are intensively involved and fulfil diverse roles within the care process that surrounds ANH decisions in patients with dementia.²⁸ 'Realizing good care' is their guiding principle, which is grounded in 'being touched by the vulnerability of the patient'. This central experience greatly influenced the nurses professionally and personally: It was clearly felt through the interviews that this determined their actions, emotions, and thoughts during the ANH care process.

The relationship between nurses' engagement and patient vulnerability, as described in our results, prompted us to examine the works of authors that explored care perspectives in healthcare ethics. For instance, our findings fit Walker's²⁹ description of care practices as practices of responsibility in which the different persons involved realize responsibility towards each other and themselves by responding to

²⁸ AUTHORS

²⁹ M.U. Walker. 1998. *Moral understandings. A feminist study in ethics*. New York & London: Routledge.

vulnerability. As such, our results provide an illustration of the ethical essence of care practices, providing care in response to the vulnerability of a human being in order to maintain his/her dignity.³⁰

In our study, the ethically sensitive response of the nurses was clearly perceptible through their stories.³¹ Tronto's³² framework of care as an ongoing process consisting of four dimensions is helpful for interpreting our results. In addition to the concrete 'caregiving' dimension, she identifies three other dimensions: 'caring about', noting the existence of a need; 'caring for', recognizing that one can act to address the unmet needs of another; and 'care receiving', knowing that caring needs have been met. In our study, 'caring about' occurred when the nurses' first met the demented patient and continued as the nurses' attentively observed and recognized the patient's vulnerability. 'Caring for' lies in the responsibility our nurses took to respond as best as possible to this vulnerable appeal. 'Care receiving' refers to the fact that

³⁰ H.M. Chochinov. 2007. Dignity and the essence of medicine: the A, B, C and D of dignity conserving care. *BMJ* 2007; 335: 184-187.

³¹ AUTHORS

³² J. Tronto. 1993. *Moral boundaries. A political argument for an ethic of care*. New York: Routledge.

all nurses in our study reflected on the process and evaluated it from the perspective of the patient's well-being, the family, their colleagues, and themselves, leaving the process behind with rather positive or negative feelings. Thus, according to Tronto's³³ framework, our interviewees gained the potential to provide optimal care as they acquired the essential attitudes of attentiveness, responsibility, competency, and responsiveness.

Nevertheless, clinical-ethical decision-making goes further than the caregiver-patient relationship. 'Realizing good care' for an individual patient should be the result of deliberation between all actors involved. It is in the middle of this complex tangle of strong and conflicting attitudes, intuitions, and arguments that the right decision for the patient has to be made.³⁴ Along these lines, from the interviews we identified three main actors in the ANH decision-making process in addition to the patient and the nurse: the physician, the family, and the nursing team. These actors constitute the relational context and clearly had great impact on the nurses' experiences during the entire ANH decision-

³³ Tronto, op. cit. note 31.

³⁴ AUTHORS

making process. The central ethically sensitive question modifying the nurses' experiences was: Within the prevailing relational context, were the nurses able to respond to the patient's vulnerable request in a way that respected his/her dignity?

Indeed, notwithstanding their close and continuous involvement with their patients, nurses are neither more nor less than one party between all other parties involved in this ethical decision-making process, holding competing or corresponding values. In the end, it is the physician who carries the final responsibility. A nurse's position, previously characterized as an 'in-between' position,³⁵ creates a rather conflicting assignment: respond to the appeal of the patient versus depend on others to respond. This phenomenon is expressed in the concept of the 'moral position of the caregiver', which refers to how the caregivers' institutional position influences how they deal with ethical problems and whether they participate in ethical decision-making.³⁶

³⁵ A. Bishop & S. Scudder. 1996. Nursing ethics: holistic caring practice. Boston: Jones and Bartlett Publishers.

³⁶ V. James, D. Field. Who has the Power? Some Problems and Issues Affecting the Nursing Care of Dying Patients. *Eur J Cancer Care* 1996; 5: 73-80.

In the interviews, we observed that the nurses' experiences differed depending on the contextual circumstances. If the surrounding context was supportive and the final decision respected the dignity of the patient, then the nurses were satisfied and felt they contributed valuably. However, if the nurses did not have the opportunity to fully participate in the decision-making process and did not agree with the final decision, then they had negative contrast experiences. Schillebeeckx³⁷ described negative contrast experiences as an emotional reaction against morally bad behaviour. Experiencing this contrast caused nurses to criticize the other parties: the contrast between what the nurses considered to be dignified care and the actual care provided in real practice, which was influenced by the patient's current situation and the nurses' upbringing, education, and life experiences. This indignation motivates nurses to change things in order to undo the contrasting event and to promote patient well-being.³⁸

Nevertheless, if the interviewees were unable to reduce patient suffering and had to execute decisions they perceived as morally wrong,

³⁷ E. Schillebeeckx. Theologische draagwijdte van het magisteriële spreken over sociaal-politieke kwesties. *Concilium* 1968; 4: 21-40.

³⁸ AUTHORS

they experienced intense negative emotions such as powerlessness, frustration, anger, disbelief, indignation, and disgust. Regular confrontation with such situations can lead to moral distress.³⁹ According to Jameton,⁴⁰ nurses experience moral distress when they judge a particular decision to be ethically correct but are unable to execute it because of situational factors. Several studies warn of the negative consequences of living and working with moral distress: providing less personalized care, decreased job satisfaction, health problems, and burnout with nurses leaving the profession.⁴¹ In some nurses we observed the worrisome evolution of nurses 'being touched' to 'being resigned' because of their inability to overcome factors preventing them from providing ethically correct care. In this type of

³⁹ S. Kävelmark et al. Living with Conflicts-ethical Dilemmas and Moral Distress in the Health Care System. *Soc Sci Med* 2004; 58: 1075-1084; K.M. Gutierrez. Critical Care Nurses' Perceptions of and Responses to Moral Distress. *Dimens Crit Care Nurs* 2005; 24: 229-241; K. Torjuul & V. Sorlie. Nursing is Different than Medicine: Ethical Difficulties in the Process of Care in Surgical Units. *J Adv Nurs* 2006; 56: 404-413.

⁴⁰ A. Jameton. 1984. *Nursing Practice: The Ethical Issues*. NJ: Prentice-Hall Englewood Cliffs.

⁴¹ Kävelmark et al., *op. cit.* note 37.; Gutierrez, *op. cit.* note 37.; Torjuul & Sorlie, *op. cit.* note 37.

situation, the nurses' crucial and valuable role as the patient's skilled companion is threatened.⁴²

Interestingly, in addition to voicing their conviction about what was 'good' or 'bad' for the patient, several nurses experienced feelings of uncertainty. Due to the patient's incompetency and hence inability to express his/her wishes and due to the unpredictable outcome of ANH, nurses could never be fully certain about the most optimal decision. In their qualitative study of doctors' and nurses' perceptions of ethical problems in end-of-life decisions, Oberle and Hughes⁴³ observed paradoxal thinking in the nurses' responses: On the one hand, they expressed concern that the doctor made the wrong decisions; and on the other hand, they recognized that outcomes are uncertain and that a patient's wishes are seldom clear. Indeed, during clinical-ethical decision-making, and especially when confronted with life-threatening situations, viewpoints of what constitutes 'best care' are never completely clear to those involved. There is no such thing as direct

⁴² A. Titchen. 2000. *Professional Craft Knowledge in Patient-Centered Nursing and the Facilitation of its Development*. Doctoral dissertation. Oxford: Oxford University.

⁴³ K. Oberle, D. Hughes. Doctors' and Nurses' Perceptions of Ethical Problems in End-of-life Decisions. *J Adv Nurs* 2001; 33: 707-715.

access to the patients' current wishes. What patients would have wanted under the specific circumstances needs to be constructed with all involved based on what is known of their life, previous pronouncements and present reactions to certain acts.⁴⁴ Notable is that none of the patients discussed by our interviewees had an advance directive. Notwithstanding such formulations cannot relieve the doubts of decision-makers and although the validity and effectiveness of advance directives in patients with dementia is under question,⁴⁵ these directives may serve as a valuable instrument to structure communication about treatment decisions and to diminish feelings of uncertainty.⁴⁶

⁴⁴ C. Gastmans. 2002. Towards integrated clinical ethics approach: caring, clinical and organizational. In *Healthy Thoughts: European Perspectives on Health Care Ethics*. K. Lie, P.T. Schotsmans, B. Hansen, T. Meulenbergs, ed. Leuven: Peeters: 81-102.

⁴⁵ C.A. Monturo, N.E. Strumpf. Advance Directives at End-of-life: Nursing Home Resident Preferences for Artificial Nutrition. *J Am Med Dir Assoc* 2007; 8:224-22; Triplett et al., *op. cit.* note 9.; de Boer et al., *op. cit.* note 9.

⁴⁶ G.A. Widdershoven & R.L. Berghmans. Advance Directives in Dementia care: from Instructions to Instruments. *Patient Educ Couns* 2001; 44:179-186.

Practical implications

Nurses' involvement in decision-making processes concerning ANH in patients with dementia is a difficult and complex experience. Nurses often have strong convictions about what constitutes 'good care'; however, they must also consider the values and expectations of others' involved. On the one hand, the feeling of 'being touched' can be considered to be a strength, as it underlies the motivation to realize good care. On the other hand, 'being touched' can be considered to be a weakness, as it may make nurses vulnerable to moral distress due to contextual influences. Therefore, nurses have to be supported in their ethically sensitive assignment:

Next to self-development of knowledge and skills,⁴⁷ nurses should be trained to cultivate open interpretative dialogue with the other caregivers involved. Indeed, clinical-ethical decision making concerning ANH also incorporates a dialogical aspect. It is necessary that all involved are motivated and capable to evaluate critically the own

⁴⁷ R.P. Lopez et al. Nurses' Perspectives on Feeding Decisions for Nursing Home Residents with Advanced Dementia. *J Clin Nurs* 2010; 19: 632-638.

opinions and to explore jointly the possible care alternatives. Linking all the different viewpoints can lessen the nurses' feelings of uncertainty, reach consensus, and increase understanding of the decisions taken.⁴⁸

When it comes to decision-making concerning such a basic part of life such as eating, sufficient support is needed for nurses who guide family members subject to great emotional distress.⁴⁹ Furthermore, developing multidisciplinary professional guidelines that explicitly describe the specific roles of all parties involved will clarify the position of nurses in the ANH decision-making process.⁵⁰ As research has shown, integrating these guidelines into clear evidence-based and ethically responsive institutional ethics policies will not only enhance these policies but also will provide caregivers with guidance to support

⁴⁸ Gastmans, *op. cit.* note 44.

⁴⁹ van der Riet et al., *op. cit.* note 7; Eggenberger & Nelms propose a nurse-lead consensus building approach to guide family decision-making regarding ANH in patients with dementia. This framework can be used to guide nurses in their family interactions. S.K. Eggenberger & T.P. Nelms. Artificial Hydration and Nutrition in Advanced Alzheimer's Disease: Facilitating Family Decision-making. *J Clin Nurs* 2004; 13: 61-67.

⁵⁰ AUTHORS

them as persons and as professionals during complex ethical decision-making processes.⁵¹

Suggestions for further research

Our research provided a rich and in-depth view of nurses' experiences during ANH decision-making in hospitalized patients with dementia. As the focus of the study was quite narrow, it would be interesting to broaden this starting point to other settings (e.g. nursing homes, home care) and patient populations (e.g. Parkinson's disease patients, oncology patients) for contradictions or similarities in nurses' experiences. Further, as our study revealed influences of other persons involved on the nurses' experiences, we assume that nurses themselves also have a certain influence. Therefore, to reach mutual understanding and respect, it would be interesting to map out the experiences of others involved (physicians, family, etc.) during ANH decision-making.

⁵¹ AUTHORS

ACKNOWLEDGMENTS

The authors thank all the participants for contributing to this study.

We are also thankful to ANONYMOUS for participating in the peer-review process.